

# Sickle-cell disease spreads

## Medical centers adjust how they look for and treat the blood disease as it grows among Latinos

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Leivi Vaeriano comforts her son, 19-month-old Adrian Perez-Vaeriano, as they wait to begin the boy's monthly blood transfusion, necessary because of his sickle-cell disease. The University of Colorado's Sickle Cell Treatment and Research Center identifies about 10 new cases a year of the disease, once associated mainly with African-Americans. (Joe Amon, The Denver Post )

The painful blood disorder called sickle-cell disease is striking an increasing number of Latino people in Colorado, according to University of Colorado researchers.

The trend in the disease — long associated with African-Americans — is worrying because many Latinos aren't as aware of the risks, said Kathy Hassell, medical director of the university's Sickle Cell Treatment and Research Center.

"Obstetricians have gotten pretty good at screening African-American women, but they don't think about Ms. Lopez or Ms. Gonzales," Hassell said. "There's no word in Spanish for sickle cell."

Hassell has been tracking the percentage of babies born every year with a single sickle-cell gene — the disease occurs only in those who get a sickle-cell gene from both mother and father.

The percentage of sickle-cell carriers who are Latino has jumped from 10 percent to 32 percent in the last 20 years — a time when the Latino population in Colorado has more than doubled, according to U.S. census figures.

The Sickle Cell Center is beginning to print educational brochures in Spanish, and it's making sure translators are available to counsel patients.

"This may be the tip of the iceberg," Hassell said.

Sickle-cell disease is named for the crescent-shaped red blood cells that mark the illness. Normal red blood cells are smooth and round.

Because those sickle red blood cells don't carry oxygen effectively, people with the disease are often anemic.

The Colorado center identifies about 10 new cases a year among the state's 75,000 newborns.

Sickle-cell patients are vulnerable to life-threatening infections, may have strokes as children, often die in their 40s or 50s and have intense "pain crises" requiring hospitalization.

Preventive measures — such as daily penicillin drops for babies — can reduce the number of organ-damaging infections, triggered because the spleen can't effectively filter sickled blood.

"It used to be that 30 percent of children died before (age) 5 of overwhelming infection," Hassell said. "Now, every newborn in the state is screened, and we try to send a nurse to the family's home for education."

Thursday morning at The Children's Hospital sickle center in Aurora, 19-month-old Adrian Perez-Vaoeriano sat tearful on his mother's lap, taking shaky breaths as the two waited for blood-test results.

A batch of donated red blood cells was a good match, so Adrian started his seventh red-blood-cell transfusion — a monthly six-hour ritual he'll continue until he's at least 2 years old.

Soon after he turned 1, the left side of his belly became rock-hard, said his mother, Leivi Vaoeriano.

She rushed him to Children's Hospital, where doctors used a transfusion to clear the sickle blood clogged in his spleen, nurse coordinator Laura Cole said.

"When he's 2, they'll take out his spleen," Cole said.

Adrian's mother said she was baffled by her son's diagnosis, which she learned about when he was about 2 months old.

"I just didn't know what it was," Vaoeriano said.

Some of her family members had heard of the disease, she said, but they had no idea that Hispanic people got it.

"Everyone was confused. They said: 'Why does he have this? We're from Acapulco,' " Vaoeriano said.

To get sickle-cell disease, a person must inherit two mutated genes — one from each parent, Hassell said. So if the gene is cropping up more often among Latinos, it'll eventually mean more disease.

"We know this is not just an African-American disease," said Willarda Edwards, president of the Sickle Cell Disease Association of America, in Baltimore.

"I have people from Nebraska calling me saying, 'I'm not black, but I got this.' Anyone can," Edwards said.

### ***Reaching other races***

Sickle-cell disease has long been associated with African- Americans, but the gene is also common among people of Mediterranean and Indian descent, Edwards said, and increasingly in Latino populations.

The disease probably evolved in parts of the world where malaria is or was a problem, Edwards said. People with one sickle gene have some protection against malaria.

Newborn screens in every state now tell parents if their child is a carrier, but since carrying the gene doesn't cause disease, parents may forget to inform their children later on.

When two people who each carry the gene have a child, the chance is 25 percent that the baby will have sickle-cell disease.

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