# Parents of babies with sickle cell trait are less likely to receive genetic counseling, study says

11 September 2012

Parents of newborns with the sickle cell anemia trait were less likely to receive genetic counseling than parents whose babies are cystic fibrosis carriers, a new study from the University of Michigan shows.

University of Michigan researchers found that 20 percent of physicians reported their patients with newborns carrying the sickle cell trait did not get any genetic counseling. In contrast, parents of babies who were cystic fibrosis carriers received more counseling overall (92 percent vs. 80 percent).

The research was published online in the August issue of the Journal of Genetic Counseling.

"Sickle cell anemia is much more common in African Americans and cystic fibrosis is more common in non-Hispanic Whites," says Kathryn L. Moseley, assistant professor of pediatrics and communicable diseases at the University of Michigan's C.S. Mott Children's Hospital.

"Being a sickle cell carrier conveys some increased health risks, including sudden death and increased risk of severe dehydration in certain environments, but a cystic fibrosis carrier has no additional health risks," says Moseley, M.D., M.P.H. who was lead author on the study and is an investigator in U-M's Child Health Evaluation and Research Unit.

"Logically, then, one would think that parents of newborns with sickle cell trait would receive genetic counseling at least as much if not more than parents of newborn carriers of cystic fibrosis. Our study shows the opposite."

Moseley says this is believed to be the first study to ask primary care physicians about their office practices in this area. National guidelines recommend genetic counseling for parents of newborns with either the sickle cell trait or carriers of cystic fibrosis.

Between 2000 and 2009, seven student athletes with the sickle cell trait died suddenly. Those deaths led the National Collegiate Athletic Association and the National Athletic Trainers Association to issue guidelines that recommend sickle cell testing for all athletes and modification to conditioning programs for athletes with sickle cell anemia.

"Even though most children with the sickle cell trait remain healthy, all are at risk for complications under specific conditions. Parents should be aware of the potential risks and genetic counseling could provide that information," says Moseley.

This health disparity needs further investigation, Moseley says.

"Are physicians aware of the risks to individuals with the sickle cell trait, or are they minimizing them? Better methods are needed to inform the parents and physicians about the rare, but real risks to individuals with sickle cell anemia," she says.

**More information:** DOI: 10.1007/s10897-012-9537-3

Provided by University of Michigan Health System