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higan Newborn Screening Family

What is a positive newborn screen?

A screening test result that is positive for **sickle cell trait** means that your baby's blood has **both** normal cells as well as sickle cells.

You may have heard about sickle cell anemia. Sickle cell anemia, also called sickle cell disease, is very different from sickle cell trait. A baby with sickle trait will **never** have sickle cell disease.

Sickle cell trait is an inherited condition where the person has a normal red cell gene and a sickle cell gene.

Why is this test result important to you, the parent?

Many people do not know that they have sickle cell trait. If your baby has sickle cell trait, then at least one parent also has the trait. It runs in families. If you have sickle cell trait, you may pass the gene that causes sickle cell disease to your children.

If both parents have sickle cell trait, <u>they have a 1</u> in 4 chance of having a baby with sickle cell disease. This 1 in 4 chance is true for <u>every</u> pregnancy.

When your baby with sickle cell trait grows up:

 He or she could possibly have children with sickle cell disease. It depends on what genes the other parent has.

The sickle cell gene can be passed on to your children:

 It can also be passed along to your grandchildren. So, when your child gets older, let him or her know they have sickle cell trait.

Michigan Resources and Support

How can sickle cell trait affect your baby's health?

Sickle cell trait does not usually cause problems for babies or children who have it. In rare cases, sickle cell trait can cause a few problems. Let your doctor know if this ever happens:

- Blood in the urine from time to time.
- Some pain or discomfort at high altitudes. (for example, in the mountains or in certain cities that are high above sea level)
- Problems with extreme exercise in hot, humid weather, when not drinking enough water.

What should a parent do with this test result?

Make sure to ask your baby's doctor if the medical record includes this information. This should help avoid more testing.

When your child is older, be sure that he/she knows about the sickle cell trait and that it might pass to his or her children.

How would I find out my child has a positive trait result?

You will be notified by the Sickle Cell Disease Association of American, Michigan Chapter (SCDAA-MI) with a mailed letter and phone call.

How can I get more information?

You can obtain more information from your baby's doctor, or by contacting the Sickle Cell Disease Association of America, Michigan Chapter at (313) 864-4406 or toll free at 1-800-421-4406

You might also want to consider genetic counseling to discuss testing options and family risks.

Michigan Newborn Screening Nurse Consultant Toll-free: 1-866-673-9939 newbornscreening@michigan.gov Sickle Cell Disease Association- Michigan Chapter Phone: (313)864-4406 Toll-free: 1-800-421-8453 www.sicklecelldisease.org

Michigan Newborn Screening Follow-up, 201 Townsend St., Lansing, MI 48913, Phone 1-866-673-9939 www.michigan.gov/newbornscreening