Here are 5 things you can do.
Take time to find out more about some important things:

1. Where and how to get tested.
2. Where to get reliable advice and counseling about test results.
3. What Hemoglobin is (Hee-mo-glo-bin is a term you may hear).
4. What you should tell other family members about the Trait and why.
5. Anything else you want to know about Sickle Cell Disease and Trait.

Individuals with Sickle Cell Trait should inform their doctor about their condition. If you have further questions please contact:

Your local Sickle Cell Disease Organization Quest to Cure at:
www.questtocure.org

Office for Children with Special Healthcare Needs
602-542-1860 or 1-800-232-1676
http://www.azdhs.gov/phs/ocshcn

Raising Special Kids
602-242-4366
Toll Free: 800-237-3007
Fax 602-242-4306
www.raisingspecialkids.org

National Coordinating and Evaluation Center
Sickle Cell Disease and Newborn Screening Program
Contact National Coordinating and Evaluation Center:
410-528-1555 (Phone)
410-528-1495 (Fax)
1-800-421-8453 (Toll Free)
www.sicklecelldisease.net
HERE ARE 5 THINGS YOU SHOULD KNOW

Here is just one example. Get tested to find out what genes YOU have. Each parent has 2 genes. And each parent passes 1 gene along to the baby. So, with each pregnancy, these 2 parents could have a baby with any one of these pairs of genes. It just depends on how their genes combine.

Put a check (✓) next to each point that you understand.

1. At least one of your baby’s parents has a Sickle gene (S).
   - Genes are what cause parents to pass traits (like eye color) or conditions (like Diabetes) along to their children.
   - One parent passed a Sickle gene (S) along to your new baby. One parent passed a Normal gene (A) along. This is no one’s fault. It just happens (See the example above).
   - Sickle Cell Trait (AS) occurs when a person inherits a Normal gene (A) from one parent, and a Sickle gene (S) from the other parent. So, it is not something you “catch”.
   - The Sickle gene (S) is the one to be aware of. If it had combined with a gene other than the Normal gene (A), your baby could have had Sickle Cell Disease.

2. Your new baby does NOT have Sickle Cell Disease.
   - Sickle Cell Disease is serious and can be very painful. Sickle Cell Disease is a disease of red blood cells.
   - Sickle Cell Trait is usually a very mild condition. Most people with Sickle Cell Trait never even know that they have it. They carry a Sickle gene (S). But their Normal (A) gene keeps them from getting really sick.
   - Millions of people have Sickle Cell Trait and they are fine. There are football players, firefighters, and other very active people who have Sickle Cell Trait.

3. IMPORTANT: You CAN possibly have a baby with Sickle Cell Disease, in the future.
   - This can happen if either you or the other parent has an (S) gene (a Sickle gene). Be aware of this.
   - This is the main reason to know that your baby has Sickle Cell Trait (AS). The Sickle gene (S) can cause problems if it combines with a gene other than the Normal gene (A).
   - Both parents do NOT have to be (AS) for this to happen.
   - Get tested to find out if this could apply to you. If you have already been tested, make sure the results were detailed and correct.

4. This Sickle gene (S) can affect your child’s children, in the future. It runs in families.
   - When your baby with Sickle Cell Trait (AS) grows up: he or she could possibly have children with Sickle Cell Disease. It depends on what genes the other parent has.
   - This Sickle gene (S) can be passed along. It can be passed along to your grandchildren. So, when your child gets older, let him or her know this.

5. In RARE cases, Sickle Cell Trait (AS) can cause a few problems.
   - A few people with Sickle Cell Trait may sometimes have certain problems. Let a doctor know if this ever happens:
     - Blood in the urine, from time to time.
     - Some pain or discomfort at high altitudes (like 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.

Sickle Cell Trait can never turn into Sickle Cell Disease.