### Sickle Cell Disease Association of America – Mobile Chapter, Inc. Trait Education (Newborn Screening Counseling)

Staff that have been certified as Sickle Cell Counselor/Educators provide education during counseling appointments with parents/guardians and families of babies born with trait conditions.

During the appointment, the Sickle Cell Counselor/Educator:

- Provides the parents/family the child's results
- Assess the parents'/family's knowledge of sickle cell trait and disease
- Explains that trait is benign (trait, is not disease)
- Explains the structure and function of hemoglobin
- Discusses the differences between trait and disease
- Demonstrate risk by explaining patterns of inheritance (Visual aids used are included)
- Emphasize the importance of telling child his or her trait status, especially at reproductive age
- Discuss incidence and epidemiology of sickle cell trait and disease
- Explain the complications that have been associated with trait. Emphasize that they are very rare and are usually easy to prevent.
- Inform parents/family members that we offer testing if the parents are not aware of their sickle cell status

### Sickle Cell Disease Association of America – Mobile Chapter, Inc. Procedures for Disease Client Education

#### Confirm Status

#### I. Assessment

- o Intake
- o Service Plan Development
- $\circ$  Evaluation
- $\circ$  Follow up

#### II. Disease Education

- Complications and manifestations
- o Genetic inheritance
- Treatment(s)

#### III. Education & Linkage to Community/Public Resources

- SCDAA Services
- Medical Services
- Insurance (i.e. Medicaid/Private)
- Food stamps
- Local Food Banks
- o Vocational Rehabilitation
- SSI/Disability

#### IV. Education regarding Health

- o Hydration
- Nutrition/Diet
- o Contraceptive Use
- Physical Care (heat, massage, therapies)
- o Immunizations
- Developmental Expectations

#### V. Medical Home Placement

- o Referrals
- Education on Compliancy

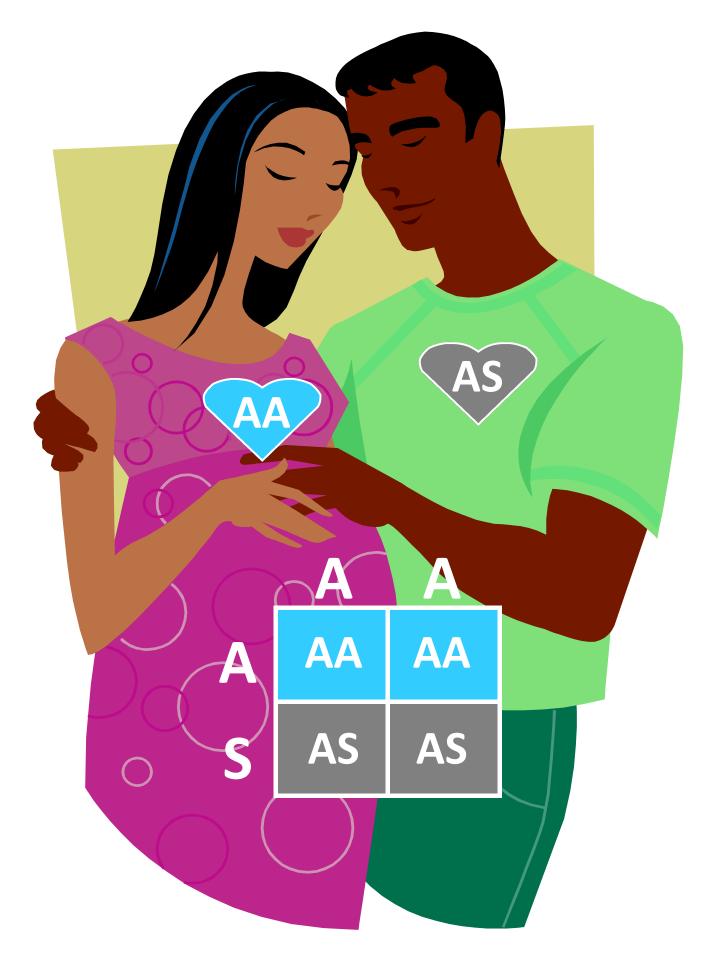
### Sickle Cell Disease Association of America – Mobile Chapter, Inc. Sickle Trait and Disease Education (General Public)

Staff that have been certified as Sickle Cell Counselor/Educators provide education presentations by request.

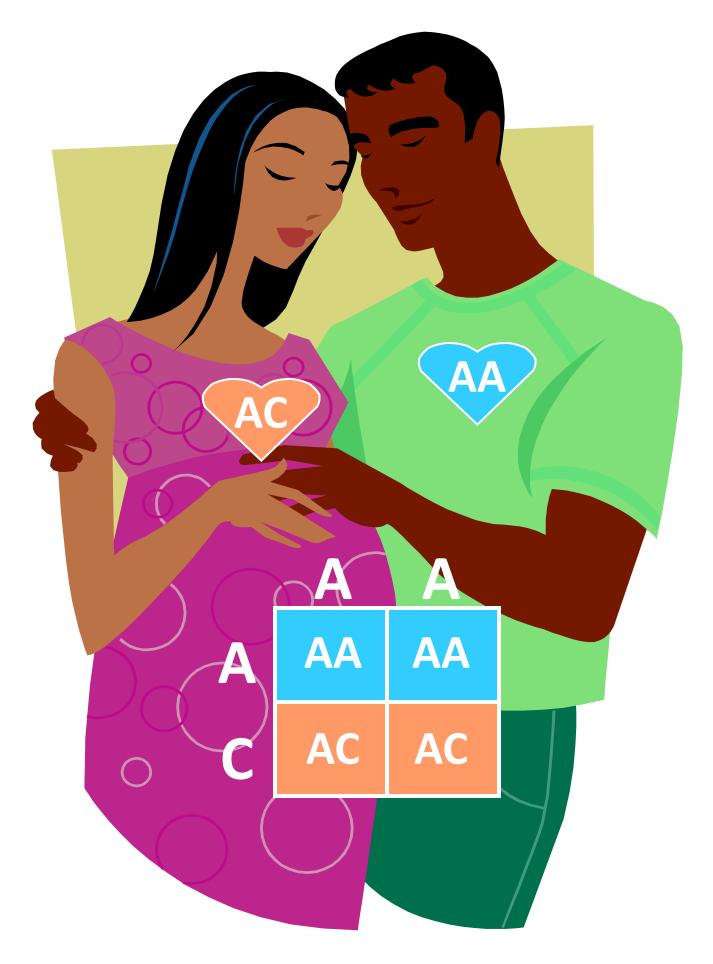
The content of presentations and education include:

- Discuss incidence and epidemiology of sickle cell trait and disease
- Discusses the differences between trait and disease
- Explains the structure and function of hemoglobin
- Demonstrate patterns of inheritance (Visual aids used are included)
- Explain what happens when the red blood cells sickle
- Explain some of the complications associated with sickle cell disease, including that there is no universal cure
- Explains that trait is benign (trait, is not disease)
- Emphasize the importance of knowing one's sickle cell status, especially at reproductive age

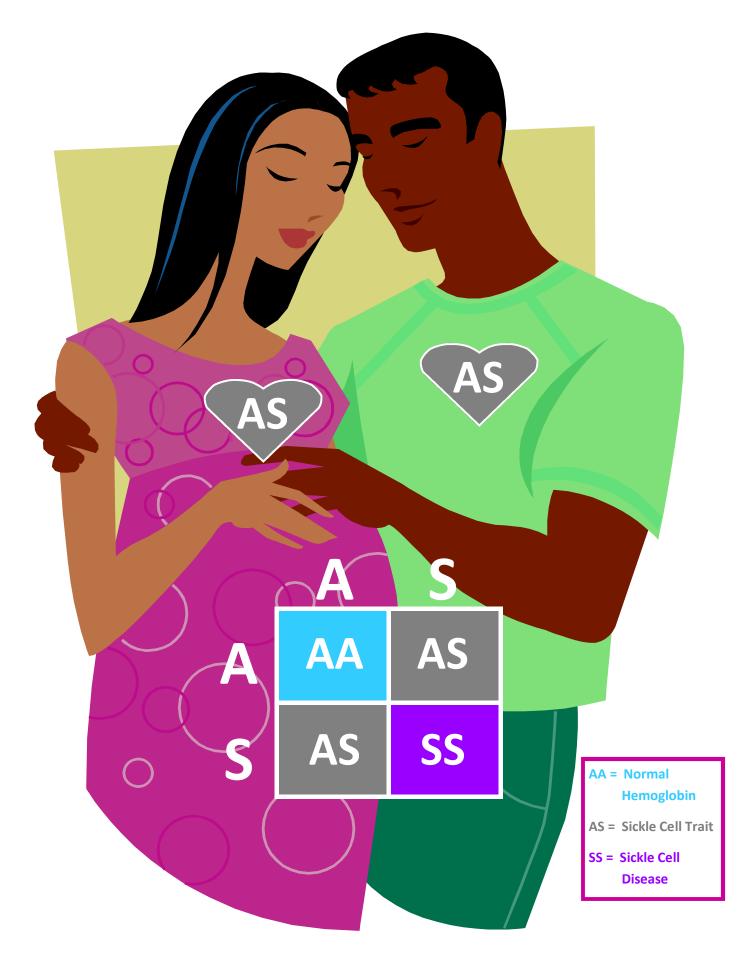
# Inheritance of Sickle Cell Trait (AS)



# Inheritance of Sickle C Disease (SC)

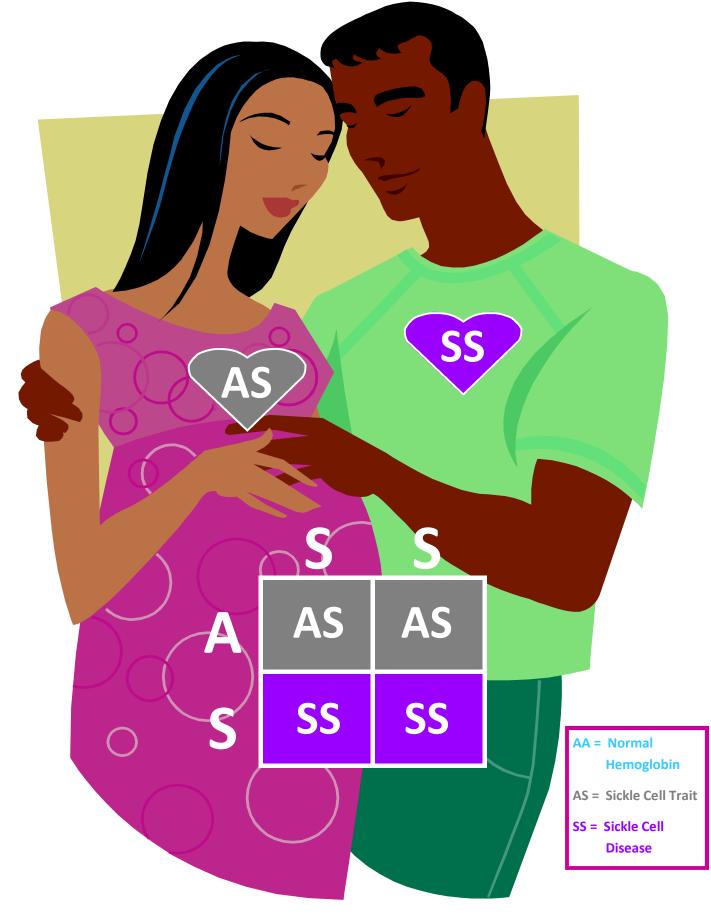


# Inheritance of Sickle Cell Disease (SS)



### Inheritance of Sickle Cell Trait & Disease (AS & SS)

One Parent has Sickle Cell Trait (AS) and the other had Disease (SS)



## Inheritance of Sickle C Disease (SC)

