

Sickle Cell Disease and Other Hemoglobinopathies: Newborn Screening and Beyond

**Satellite Conference and Live Webcast
Friday, March 24, 2017
1:00 – 3:00 p.m. Central Time**

Produced by the Alabama Department of Public Health
Distance Learning and Telehealth Division

Faculty

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Executive Director
Sickle Cell Disease Association
of America – Mobile Chapter, Inc.**

Sickle Cell Disease Association of America – Mobile Chapter (SCDAA-MC)

Mission Statement

- *To empower our clients and families with knowledge through quality comprehensive programs and services*

SCDAA – MC At-A-Glance Client & Counseling Services

- Case Management
- Transportation
- After-School Tutorials
- Summer Enrichment Programs
- Parent Advocacy Groups
- New Born Screening (NBS) Trait Counseling
- Child and Adult Trait Counseling
- Trait Counseling at Local Health Departments

SCDAA – MC At-A-Glance Testing and Education

- Health Fairs
- Visiting Public Schools
- In-Office Testing
- Sickle Cell Counselor / Educator Certification Program

Genetic Counseling for Hemoglobinopathies

Components of a Counseling Session

- Genetic counseling is the process by which patients, clients, and / or relatives, who are at risk of an inherited disorder, are advised of the consequences and nature of the disorder, the probability of developing or transmitting it, and the options open to them in management and family planning

As a Sickle Cell Counselor, you may be asked to counsel individuals with:

- Sickle Cell Disease or Sickle Cell Trait
- Hemoglobin C Trait, and other trait variants like AD, AE, AN-Baltimore, etc.
- Sickle Hemoglobin C (SC) Disease
- Sickle Beta Thalassemia Disease (SB+ or SB₀)

As a Sickle Cell Counselor, you may be asked to counsel individuals with:

- Bart's Hemoglobin (H): Alpha Thalassemia Trait or Hemoglobin H (Alpha Thalassemia) Disease
- Cooley's Anemia (Beta Thalassemia Major)
- Beta Thalassemia Trait



As a Sickle Cell Counselor, you may be asked to counsel individuals with:

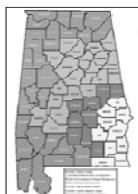
- Hereditary Persistence of Fetal Hemoglobin
- Other disease variants like CC, etc.
- Combinations of disease or trait variants like FAS+Bart's less than 10%, SC Disease w/ HPFH, etc.

Definition of a Formal Counseling Session for the CBOs in Alabama

- "A face-to-face targeted session in which a counselor is providing information to a specific client whose individual sickle cell test results are known by the counselor" – ASCORC
- *Other states' CBOs (like California) allow telephone counseling

Definition of a Formal Counseling Session for the CBOs in Alabama

- Telephone notification of results is sometimes done by pediatricians' offices or the ADPH*



Components of a Counseling Session

- Session length
- Preparing for session
- Greeting
- Provide results
- Family Assessment
- Clarify difference between SCT & SCD
- Explain patterns of inheritance
- Provide visual aids
- Discuss incidence & epidemiology
- Explain rare complications associated with SCT
- Discuss testing and offer if available
- Conclude Session

Sickle Cell Educator / Counselor Certification Program

Goals

- To provide training in education and counseling for individuals diagnosed with sickle cell disease, sickle cell trait, and other related hemoglobinopathies;
- To offer education about these disorders to health care professionals, paraprofessionals, as well as to individuals directly affected by sickle cell disease and other interested audiences

Sickle Cell Educator / Counselor Certification Program

Requirements

- Attend all sessions of the 4-day program
- Conduct an educational presentation on any aspect of sickle cell disease or any other abnormal hemoglobin
- Successfully conduct an actual counseling session under the supervision of program staff

Sickle Cell Educator / Counselor Certification Program

Requirements

- Achieve a passing score of 80% or higher on the final examination
- Re-test must be taken within three months if a score of 80% was not achieved on the final examination
 - Failure to pass the re-test will result in the individual having to re-enroll in the Sickle Cell Certification Program

Sickle Cell Educator / Counselor Certification Program Course Outline

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|--|---------------------------------------|
| • Intro. to Genetics | • Diagnostic techniques for detection |
| • Hemoglobin & hemoglobinopathies | • Prenatal diagnosis |
| • Difference between sickle cell trait, anemia, disease & other hemoglobinopathies | • Newborn screening |
| • History & geographic distribution of sickle cell disease | • Education as focal point |
| • Intro. to Thalassemia | • Psychosocial issues |
| • Pathophysiology and medical management of sickle cell disease | • Ethical issues |
| | • Diversity in healthcare |

Genetic Counseling for Hemoglobinopathies

- Questions?
- Comments?

