



Division of Public Health Services

Bureau of State Laboratory Services

Office of Newborn Screening

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Understanding the New Protocol for Hemoglobinopathies

The Newborn Screening Case Management Program will implement a new protocol for tracking and management of abnormal results for Hemoglobinopathies detected by the newborn screen starting February 13, 2012. The new follow up protocol for abnormal results for Hemoglobinopathies will be handled as follows:

Primary Hemoglobin Disorders: FS, FSA, FSC

NO CHANGE in follow up. This means that the follow up program will continue to notify and work with the Primary Care Physician (PCP), family and contracted hematologists until a final diagnosis is obtained.

Other hemoglobin disorders: FC, FE, FU, Hemoglobin H Disease, or others

Notification of results by fax to the ADHS contracted hematologist. Laboratory results will be mailed to the submitting agency and the PCP. No further follow up with PCP or family. It will be the role of the PCP to inform parents about the results and consult with a pediatric hematologist.

Hemoglobin Traits: FAS, FAC, FAE/O, FAD/G, FAU, Barts and other traits

The Office of Newborn Screening will discontinue follow up for hemoglobin traits with the family. Laboratory results will still be mailed to the PCP. It will be the role of the PCP to inform parents about the results. Advice and special considerations for infants with hemoglobin traits are available at www.aznewborn.com. In addition, the Office of Newborn Screening will conduct outreach activities with community health clinics, parent support groups, and providers on available resources.

In collaboration with the Office for Children with Special Health Care Needs, we will also be providing educational materials in English and Spanish for Sickle Cell Trait. If you would like to order brochures or would like to schedule an educational workshop in your community, please contact Sondi Aponte, Quality Improvement and Outreach Manager, at 602-364-1642.

The State Public Health laboratory anticipates no impact on the Program's ability to detect and coordinate confirmatory diagnostic testing and treatment for affected infants. The new follow up protocol for abnormal results for Hemoglobinopathies is described in the letter attached.

If you have questions or concerns regarding this information, please do not hesitate to contact myself or Ward Jacox, Chief of the Office of Newborn Screening at ward.jacox@azdhs.gov or (602) 364-1410.