

EHDI Workgroup
A piece of the Region 4 Genetics Tapestry

Region 4 Vision: All newborns will receive state-of-the-art newborn screening and follow-up; children and youth with heritable disorders will have access to genetic expertise and coordinated care in the context of a medical home.

❖ Follow-up Workgroup

Assumptions:

- Effective follow-up for children with heritable disorders provides “just in time information” to the child’s family and medical home.
- Statewide service systems such as newborn screening, early hearing detection programs, birth defects registries and early intervention programs provide opportunities to identify children with heritable disorders and initiate the continuum of follow-up activities.

Focus: The Follow-Up Workgroup will focus on protocols and practices for providing information to primary care providers and families at the time of identification (positive screen or report) and improving communication practices between those identifying children with a heritable disorder and the primary care physician.

Goal: The goal of the Follow-up work group is to develop and distribute best practice follow-up protocols and practice models for population-based identification of children with heritable disorders.

❖ EHDI Follow-Up workgroup:

Goal: develop and distribute best practice follow-up protocols and practice models for children identified by UNHS or other EHDI services (populations based, positive screen) who also may be children who have heritable disorders.

Outcome: improved access to genetic services for families whose infants have been diagnosed with hearing loss through universal newborn hearing screening or other state Early Hearing, Detection and Intervention services.

Objectives:

- Develop follow-up protocols and practices for providing information to primary care providers and families at the time of identification (positive screen or reports);
- Improve communication practices between those identifying children with a heritable disorder and the primary care physician; and
- Share follow-up protocols with Region 4 partners, other Regional Collaboratives and national audiences.

