

# State Systems Follow-up Workgroup FOLLOW-UP PROGRAMS SURVEY

## Organization Background Information

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### *Region 4 Genetics Collaborative*

Region 4 is one of seven regional collaboratives in the United States. Our Region includes seven states (Illinois, Indiana, Kentucky, Michigan, Minnesota, Ohio and Wisconsin) and a variety of stakeholders including: parents, primary care providers, specialists, laboratorians, and representatives from public health agencies and universities.

### 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.

### Mission

1. Increase access to information about newborn screening and genetic resources, services and family support systems
2. Facilitate data collection and analysis to guide decision-making regarding screening cut-offs, diagnosis and long term treatment of heritable disorders
3. Support state public health agencies in improving infrastructure for genetic service delivery to children with heritable disorders
4. Provide a forum for families, public health, and clinical providers to share best practices and models for improving newborn screening, follow-up and genetic care coordination
5. Link Region 4 states with regional and national initiatives for improving the quality of newborn screening and genetic service delivery.

### *State Systems Follow-up Workgroup*

Working towards item #3 of the Region 4 mission, the State Systems Follow-up (SSFU) Workgroup is comprised of five public health agency representatives from each of the Region's seven states.

In April 2010, the workgroup met face to face to start work on improving public health infrastructure for more effective delivery of services. The group concluded that effective follow-up for children with heritable disorders provide "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, children with special health care needs and early intervention programs provide opportunities to identify children with heritable disorders and initiate the continuum of follow-up activities. Given these statements, the SSFU will focus on protocols and practices for an integrated follow-up system that increases access to genetic services for children with heritable conditions.

### *Workgroup Charge*

Explore models and outcomes to identify and recommended promising practices for state implementation (of whole model or parts) to improve their own systems for children with heritable conditions and their families.