



Responsibilities of the Colorado Newborn Screening Program are:

- Ensuring that newborn screening occurs for all newborn babies in the state for the disorders mandated by CRS 25-4-801 through 25-4-804 and CRS 25-4-1001 through 25-4-1006, CRS 25-4-1004.7.
- Verifying that each newborn has had access to screening and if not, taking action to assure screening is available
- Providing appropriate follow up and referrals to health care providers for newborns with abnormal screening results to facilitate time sensitive repeat/confirmatory testing and treatment services
- Consulting with healthcare providers and sub-specialists regarding test implications and appropriate follow up actions
- Providing consultation, technical assistance, and education about the newborn screening program to hospitals, health care providers, parents/families of affected newborns, and community partners
- Collecting, analyzing, and disseminating data on newborn screening requirements, including cost effectiveness of the system and health outcome
- Evaluating outcomes of the program, ongoing quality improvement, and promoting continued access to appropriate specialty health care

Responsibilities of the primary health care providers and facilities are:

- Ensuring that newborn screening occurs and those results are known
- Serving as the linkage between the NBS Program and the affected newborn and family
- Being the first contact in transmitting out-of-range or invalid screening results
- Communicating the results in a knowledgeable and sensitive fashion to the families
- Serving as a resource for the families and the NBS Program
- Assisting with appropriate actions
- Facilitating repeat or confirmatory testing and appropriate sub-specialty care
- Reporting the results of the confirmatory tests and the diagnosis to the NBS Program

Responsibilities of the families are:

- Identifying a primary health provider (if appropriate) for result reporting by the time the newborn is discharged from the birth facility
- Providing accurate, complete demographic information, in order to facilitate follow up
- Verifying that newborn screening occurs and those results are known
- Assisting with appropriate actions taken in response to out-of-range results or invalid screening
- Participating in decision-making around possible interventions and ensuring adherence to the decided course of action

Responsibilities of the pediatric sub-specialty providers in newborn screening follow up are:

- Assisting with development of confirmatory and diagnostic protocols
- Assisting with confirmatory and diagnostic evaluations and other interventions
- Providing clinical/medical advice to the newborn screening program
- Collecting and sharing information for effective patient management and system evaluation
- Collaborating with primary healthcare providers to establish shared management plans in partnership with the child and family

