Texas State Newborn Case Management Program (Government/USA)
http://www.dshs.state.tx.us/newborn/

Section I: Summary

The goal of the Newborn Screening Case Management Program is to decrease the morbidity and mortality of infants born in Texas through customer-oriented, high quality newborn screening follow-up, case management and outreach education. The program offers free, in-service education on the Texas Newborn Screening Program through online website resources and educators.

Section II: Statement of Purpose

The Texas Newborn Case Management Program provides education to parents or guardians of Texas newborns about the importance of testing for 27 rare disorders through the "newborn screen." With these disorders, babies often appear healthy but require treatment as serious problems such as mental retardation, illness, or death may be prevented if the disorders are identified and treated right away.

Newborn screening began in 1962, with testing to identify infants with phenylketonuria (PKU). It has since been expanded to include many different endocrinological, metabolic and hematologic disorders, which test over 4 million babies in the United States each year. This testing helps to identify about 3,000 babies with serious diseases each year, so that they can be treated early, usually before symptoms develop.

Prior to being sent home from the nursery, newborns have blood drawn (usually by a heel stick) and the specimen is placed on a special filter paper, which can then be sent to a centralized lab for testing. A repeat or second newborn screen is usually performed at a later time, often at the two week checkup, especially if the first test was done in the baby's first twenty-four hours of life. Some states, including Texas, mandate by law that two screens be done.

The purpose of the newborn screen is to test or examine for the presence of a disease before symptoms develop (although some children may develop symptoms before the results are known) and to help identify those infants that at most at risk for developing the particular disease. Unfortunately, normal children sometimes have an abnormal newborn screen. These children are then retested or other more comprehensive tests are done to identify those children who really have the illness. It is important to keep this in mind if you are told that your child has an abnormal newborn screen, since he may not have the illness. A positive test always has to be confirmed before a child is diagnosed with a disorder.

States have continued to expand the list of disorders which are tested for fear of overlooking what may be a treatable disorder. Because if your child is born with biotinidase deficiency, but happens to be born in a state that doesn't screen for it then he will likely develop seizues and mental retardation. On the other hand, if he was born in a state that does screening for biotinidase deficiency, then those complications could be prevented if he was identified and simply given extra biotin.

The Texas Newborn Screening Program provides parents with children testing positive for a disorder with a nurse who can offer additional information and guidance to parents. The case management specialist will send to the family lab results, ACT fact sheet (when to take a child to the doctor), fact sheets on the disorder, and a list of metabolic specialists. The program has ombudsman position to assist families, the public, health care providers, community organizations and government agencies in resolving issues such as obtaining benefits, and resolving service-related problems regarding the Newborn Screening program.

Section III: Outcomes

Of the approximately 800, 000 specimens collected annually, 15,000 specimens are flagged each year for follow-up and approximately 600 cases are diagnosed each year.

Section IV: Resources

Texas Department of State Health Services PowerPoint Presentation
http://www.dshs.state.tx.us/newborn/ppt/nbsslide.ppt#38