

Newborn Screen Positive Infant ACTion Project

Newborn genetic screening advancements provide increased opportunities for the diagnosis and treatment of rare but serious congenital conditions that affect newborn infants. Because the conditions are rare, however, they may be unfamiliar to pediatricians and other primary care providers.

Although materials to guide primary care providers in responding to conditions identified through newborn screening are readily available, the providers are largely unaware of them.

The Newborn Screen Positive Infant ACTion Project is an effort to rectify the situation, working with a broad spectrum of primary care practice teams to test strategies for improving health outcomes for affected children. The teams attend a one and a half day workshop and participate in monthly conference calls that focus on the use of American College of Medical Genetics ACTion Sheets to assist pediatricians in the short-term management of infants affected by congenital conditions identified through newborn screening.

Funding

HRSA awarded \$1 million to the American College of Medical Genetics through the Heritable Disorders grant program. From this funding, \$78,000 supported the project, which also received funding from the American Academy of Pediatrics Quality Improvement Innovation Network.

Participants

Fifteen clinical practice core improvement teams participated in the initial phase of the project, which began on June 1, 2010 and concluded November 30, 2010. Each team comprised three members: one primary care physician and two selected staff.

Key Successes

Participants report:

- *Had it not been for your study, two potential problems with serious consequences would not have been averted and two infants would have been hurt.*
- *It will help with good patient care.*
- *Through the introduction of ACT sheets...I have identified additional sources of information not only for the professional but also for the family.*
- *More kids were being missed (for newborn screening) than we thought.*

For more information: <http://www.aap.org/qualityimprovement/quiin/NBS.html>