Newborn Screening
The Role of the Title V Maternal and Child Health Services Block Grant

About AMCHP
For over 60 years the Association of Maternal and Child Health Programs (AMCHP) worked to protect the health and wellbeing of all families, especially those who are low income or underserved. AMCHP represents state public health leaders, including high level state government officials, directors of maternal and child health programs, directors of programs for children with special health care needs and adolescent health coordinators.

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Background
Newborn screening is a public health success story, enabling the early identification of infants with potentially life-threatening heritable disorders and genetic diseases. In the United States, roughly four million infants are screened for disorders. In 2002, some states were screening for only four conditions, while others were screening for up to 36. Today, 44 states and the District of Columbia require screening for at least 29 of the 31 treatable core conditions on the Recommended Uniform Screening Panel. This widespread expansion and standardization of newborn screening has led to life-saving treatments and interventions for at least 12,500 newborns diagnosed with genetic and endocrine conditions each year.

The Title V Maternal and Child Health (MCH) Services Block Grant authorized by the Social Security Act is the only federal program of its kind devoted solely to improving the health of all women and children. The Title V MCH Block Grant is critical to state efforts in implementing systems of care for children with special health care needs. Historically, funding from this program supported newborn screening, diagnosis, treatment and follow up care. State children and youth with special health care needs directors are often members of state newborn screening advisory committees and also facilitate care coordination, ensure follow up and collect the data necessary to promote quality improvement.

The Association of Maternal & Child Health Programs calls on Congress to fund the Title V MCH Block Grant at $640 million for fiscal year 2014. This funding is critical for continued state efforts to ensure the success and improvement of their newborn screening systems of care for four million infants each year.

State Spotlight Title V at Work
New Jersey law requires that every baby born in the state be screened for 54 conditions that can cause serious health problems.
The Department of Health Title V Children and Youth with Special Health Care Needs program – Special Child Health and Early Intervention Services (SCHEIS) – houses the Newborn Screening and Genetic Services Program (NSGSP), which ensures that all newborns and families affected by an abnormal screening result receive timely and appropriate follow-up services. In 2011, 101,692 newborns received initial screens and 5,421 infants had out of range results requiring the follow-up services of the NSGSP.

Follow-up services include notification and communication with parents, primary care physicians, pediatric specialists and others to ensure that the baby has immediate access to confirmatory testing and treatment. Title V maintains an organized system of care to ensure not only early identification through newborn screening and short-term linkage to care and support, but also continual follow-up for children with complex, long-term medical and developmental disabilities. For these children, prompt attention to their condition early in life helps ensure they will lead healthier lives when they are older.

In 2011, New Jersey became one of the first states to implement newborn screening for critical congenital heart defects (CCHD), which can cause serious complications within the first few days or weeks of life and often require emergency care. SCHEIS staff, along with the Centers for Disease Control and Prevention, the Health Resources and Services Administration, the American Academy of Pediatrics - New Jersey Chapter, and the New Jersey Critical Congenital Heart Disease Screening Working Group expanded the program to support and guide implementation efforts to build an effective CCHD screening and surveillance program. Implementation efforts have included identifying contacts at every birthing facility in the state, distributing a recommended screening protocol to the birthing facilities, providing trainings, and developing a parent education handout. Additionally, a surveillance mechanism was established and implemented to evaluate the impact of statewide pulse oximetry legislation. Just one day after the law mandating CCHD screening went into effect, a baby was identified through the screening test and quickly referred for life-saving surgery.¹