F I S C A L I M P A C T R E P O R T

SPONSOR King **ORIGINAL DATE** 01/30/10 **LAST UPDATED** 02/08/10 **HB** 201/aHCPAC

SHORT TITLE Add Diseases to Tests for Newborns **SB**

ANALYST Hanika-Ortiz

ESTIMATED ADDITIONAL OPERATING BUDGET IMPACT (dollars in thousands)

	FY10	FY11	FY12	3 Year Total Cost	Recurring or Non-Rec	Fund Affected
Total		$5.0-$50.0			Recurring	General Fund

(Parenthesis ( ) Indicate Expenditure Decreases)

SOURCES OF INFORMATION
LFC Files

Responses Received From
Department of Health (DOH)
Human Services Department (HSD)
Health Policy Commission (HPC)

SUMMARY

Synopsis of HCPAC Amendment

The House Consumer and Public Affairs Committee Amendment clarifies that DOH shall adopt these screening tests upon the later of January 1, 2011 or when these screening tests are reasonably available.

Synopsis of Original Bill

House Bill 201 amends the Public Health Act to require DOH to add five additional disorders to the newborn screening panel. The new disorders are (1) Acid maltase deficiency or glycogen storage disease type II, (2) Globoid cell leukodystrophy, (3) Gaucher's disease, (4) Niemann-Pick disease, and (5) Fabry disease.

FISCAL IMPLICATIONS

DOH reports that additional testing fees, follow-up fees, courier fees and programmatic processes will be incurred by the department.

HSD reports that payments to hospitals for new born care is made at a global diagnosis-related group (DRG) payment, and does not change whether these tests are performed or not.

SIGNIFICANT ISSUES

The New Mexico Newborn Screening Program (NMNBSP) provides screening for 27 genetic, metabolic, hemoglobin and endocrine disorders to over 28,000 newborns annually.

Except for hearing screening, all newborn screening tests are done using a few drops of blood from the newborn's heel. The NMNBSP contracts with the Oregon State Public Health Laboratory (OSPHL) for screening and follow-up. DOH notes that OSPHL is not aware of any newborn screening laboratory that performs screening for all of these conditions with one blood spot.

HPC notes the March of Dimes reported that in 2004, about 4,000 babies were found to have metabolic disorders and more than 12,000 to have hearing impairment through newborn screening.

DOH reports that stem-cell transplant and enzyme replacement therapy are being researched as possible treatments in the future. Dr. Heidenreich, metabolic specialist at UNM, noted that "…adding lysosomal storage diseases to newborn screening panels represents the next step in the evolution of newborn screening…technology for identifying patients from the newborn screen dried blood spot is technologically difficult and, implementation of newborn screening for these disorders has not yet been accomplished by newborn screening programs throughout the United States."

PERFORMANCE IMPLICATIONS

HPC further notes that state programs vary widely in the number and types of conditions for which they test.

DOH further notes that the national advisory body for the determination of diagnoses to be included in newborn screening panels is the *Health Resources Services Administration (HRSA) Maternal and Child Health Bureau National Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children*. None of the additional disorders named in HB 201 have been recommended yet for the newborn screening panel by this advisory body.

ADMINISTRATIVE IMPLICATIONS

The NMNBSP consists of two nurses and a medical director. DOH revised its original analysis removing the statement that additional FTE would be needed.

OTHER SUBSTANTIVE ISSUES

Synopsis on the diseases from information provided by HPC:

Acid maltase deficiency or glycogen storage disease type II - is a rare, inherited and often fatal disorder that disables the heart and muscles. Disease symptoms begin in the first months of life, with feeding problems, poor weight gain, muscle weakness, floppiness, and head lag.

Globoid cell leukodystrophy - is a rare, inherited degenerative disorder of the central and peripheral nervous systems. The disease most often affects infants, with onset before age 6 months. Symptoms include irritability, unexplained fever, limb stiffness, seizures, feeding difficulties, vomiting, and slowing of mental and motor development.

Gaucher's disease – is an inherited metabolic disorder in which harmful quantities of a fatty substance called *glucocerebroside* accumulate in the spleen, liver, lungs, bone marrow, and sometimes in the brain.

Niemann-Pick disease - refers to a group of inherited metabolic disorders in which harmful quantities of a fatty substance (lipids) accumulate in the spleen, liver, lungs, bone marrow, and the brain. Symptoms may include lack of muscle coordination, brain degeneration, learning problems, loss of muscle tone, increased sensitivity to touch, spasticity, feeding and swallowing difficulties, slurred speech, and an enlarged liver and spleen. New Mexico has the second highest incidence of Niemann-Pick disorder, with the highest percentage occurring in the Spanish American population in southern New Mexico and Colorado.

Fabry disease - is caused by the lack of or faulty enzyme needed to metabolize lipids, fat-like substances that include oils, waxes, and fatty acids. Symptoms usually begin during childhood and include burning sensations in the hands that gets worse with exercise and hot weather and small, raised reddish-purple blemishes on the skin.

ALTERNATIVES

HSD notes that the Act as it currently exists gives the authority to the Secretary of DOH to add to the list of tests after consulting with the New Mexico Pediatrics Society of the American Academy of Pediatrics.

WHAT WILL BE THE CONSEQUENCES OF NOT ENACTING THIS BILL

DOH will continue to be required to adopt screening tests for the detection of certain disorders for every newborn infant in New Mexico.

AHO/mt:mew:svb