



News Release

For Immediate Release:
Wednesday, March 23, 2005
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Utah Department of Health Preparing to Expand Newborn Tests

(Salt Lake City, UT) – The Utah Department of Health (UDOH) announced its plans today to begin testing all Utah newborns for 36 metabolic diseases beginning January 2006. Utah currently tests newborns for four disorders that otherwise might not be detected until signs and symptoms appeared, often too late to prevent disability or death.

“The expansion of newborn screening is a major advancement for children’s healthcare in Utah,” said Governor Jon M. Huntsman, Jr. “The screening should identify an additional 15 to 20 Utah infants every year in time to help them get the treatment they need to live a fuller and healthier life.” The current testing identifies about 21 infants a year in Utah who need treatment for certain disorders.

“The expanded newborn screening will help pediatricians and other healthcare providers identify rare disorders than can be easily confused with common pediatric problems,” said metabolic specialist Nicola Longo, M.D., Ph.D., professor of pediatric genetics, University of Utah School of Medicine. “Diagnosing and treating these conditions will help us prevent irreversible brain damage, permanent disabilities, and possibly death.”

The expansion of newborn screening in Utah was made possible by recent legislation that increased the allowable fee UDOH charges hospitals for newborn screening kits from \$35 to \$65. The UDOH currently charges \$31 for the screening kit, which includes the testing of two screening specimens, any needed confirmation testing, and follow-up care coordination. The new kit fee, which was part of the appropriations bill signed by Governor Huntsman, is the first step in the process to expand Utah newborn screening to include an additional 32 disorders.

The UDOH is now moving forward to implement system changes to ensure that all infants born in the state receive the expanded screening and appropriate follow-up care. Changes include upgrading the current newborn screening computer software, amending the state newborn screening rule, developing educational materials for health care professionals and families, and updating the current newborn

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screening specimen collection forms. In addition, a contract for the new screening technology will be negotiated establishing a unique public health/private health partnership in Utah.

As part of its preparation for the expanded screening, the UDOH began a pilot program in October 2003 with ARUP Laboratories and the University of Utah Hospital. The pilot project helped establish appropriate and timely follow-up procedures between the public health and private health care providers. The success of this pilot program enables the UDOH to implement statewide system changes.

“The pilot program showed that expanded newborn screening and timely follow-up could be successful with collaboration and cooperation between public health and private health care sectors,” said Dr. David Sundwall, Executive Director, UDOH. “This partnership has strengthened a basic public health program and greatly enhances the health of the newborns in Utah.”

Nationwide all states require newborn screening for at least four of the detectable diseases. “With the expansion of the Utah newborn screening program, Utah will be one of 30 states that offer testing for more than 30 diseases,” said Patricia McKenna-Clark, Public Affairs Committee Chair, March of Dimes Utah Chapter. “The expansion of newborn screening brings Utah into the forefront of national newborn screening programs.”

The new tests that will be added to the newborn screening panel include Congenital Adrenal Hyperplasia (CAH), Biotinidase Deficiency, amino acid disorders (9), including Maple Syrup Urine Disease (MSUD), organic acid disorders (11), and fatty acid oxidation disorders (10), the most common of which is Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCADD).

Current screening practices will remain in effect while the UDOH makes the changes needed for the expanded screening. Parents who wish to have expanded screening for their infants during this transition time can request special screening through their private health care provider. For more information on newborn screening, go to: www.health.utah.gov/newbornscreening

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The mission of the Utah Department of Health is to protect the public's health through preventing avoidable illness, injury, disability and premature death, assuring access to affordable, quality health care, and promoting healthy lifestyles.