DEPARTMENT OF HEALTH

News Release

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CYSTIC FIBROSIS SCREENING ADDED TO HAWAI`I'S NEWBORN SCREENING TESTING PANEL

HONOLULU - Starting September 1, 2007, babies born in the State of Hawai`i will be tested for cystic fibrosis (CF) as part of the mandated newborn screening testing panel. The decision to add CF was based on the recommendations of the Hawai`i Newborn Screening Cystic Fibrosis Task Force and agreement from the larger Hawai`i Newborn Screening Advisory Committee. With the addition of CF, Hawai`i will be screening for 32 metabolic disorders and hearing loss. This testing panel exceeds the March of Dimes and American College of Medical Genetics national newborn screening recommendations for a minimal panel.

Cystic fibrosis occurs once in every 3,700 births in the U.S. and is one of the most common inherited disorders among Caucasians. In Hawai`i, CF is common in families of mixed ethnicity. With Hawai`i's diverse ethnic population, approximately 2-3 infants out of 20,000 births each year will have cystic fibrosis.

Cystic fibrosis is a severe multi-organ inherited disease, primarily affecting the lungs and pancreas. CF causes thick, sticky mucus to build up in the lungs, increasing the risk of lung infections and making breathing difficult. Digesting food is also difficult without the aid of prescription enzymes. Death from severe lung infections and respiratory failure may occur.

More

The Cystic Fibrosis Foundation states that drug treatments, therapies, and good nutrition can lengthen and improve life for a person with cystic fibrosis. The average age of CF diagnosis in the U.S. is 14 months. Fifty per cent of Hawai`i's CF cases were diagnosed after 36 months of age. With newborn screening, the diagnosis can be made as early as 2-4 weeks so that treatment can be started earlier to improve health status in children with cystic fibrosis.

Testing for CF will not involve any additional blood samples from the newborn. The medical staff at the baby's birthing facility will draw a small blood sample, usually from the baby's heel, within the first 1-2 days after birth. The drops of blood are collected on a special filter paper form and sent to the state contracted laboratory for initial testing of 32 disorders, including cystic fibrosis. If the initial screening comes back positive for an enzyme that is elevated in newborns with cystic fibrosis, a second blood sample will be collected and tested. If the second test comes back positive, the baby has a higher risk of having cystic fibrosis, and will need further testing to confirm the diagnosis of cystic fibrosis.

In most states, including Hawai`i, the newborn screening test and follow-up are paid for by fees charged to the birthing facilities. This fee will increase from $47 to $55 to cover the addition of CF to the screening panel and increases in costs to screen for the other disorders. This change is being requested by a revision to the Newborn Metabolic Screening Administrative Rules. Most health insurance plans cover the costs of the newborn screening tests. If an infant does not have health insurance coverage, the Hawai`i Newborn Metabolic Screening Program may be contacted at (808) 733-9069 for assistance. More information about newborn screening tests in Hawai`i can be found at www.hawaiigenetics.org.

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