Oregon to Test all Newborns for Cystic Fibrosis

by Bend Weekly News Sources

Beginning next month, cystic fibrosis will be added to the panel of diseases that every Oregon baby is tested for under the state's newborn screening program.

"Until now, 80 to 85 percent of children with cystic fibrosis have gone undiagnosed for months or years in Oregon," said Michael Skeels, Ph.D., director of the State Public Health Laboratory in the Oregon Department of Human Services. "Starting next month, that's changing -- and it offers a brighter future for these children."

Skeels said that early detection is critical for improving quality and length of life for people with cystic fibrosis, because it ensures that appropriate medical treatment can start right away.

Cystic fibrosis is a genetic disorder that causes thick, sticky fluid to build up in the lungs and in the pancreas. It can lead to malnutrition and severe growth problems. As the child grows older, respiratory infections and other problems increase and become more severe, affecting lung function.

When a newborn screening test shows a high risk for cystic fibrosis, the baby's physician will immediately be informed and expert medical consultation will be made available.

"A comprehensive treatment plan is a critical aspect for survival and an improved quality of life," said Michael Wall, M.D., director of the Pediatric Cystic Fibrosis Center at Oregon Health and Science University. "We are available 24 hours a day to consult on a range of issues including respiratory therapy, nutritional counseling, lab services, social services and hospital care, if needed."

OHSU is fully accredited to provide multidisciplinary care by the national Cystic Fibrosis Foundation. Kaiser Permanente Northwest Region, also in Portland, is accredited as an Affiliate Center and provides services as well.

Newborn screening is a process by which every baby has blood drawn through a heel prick and collected on filter paper. The first sample is taken prior to hospital discharge and the second within 10 to 14 days of life. The samples are sent to the state public health laboratory where they are screened for more than 30 metabolic, endocrine and hemoglobin disorders which, if not detected, can result in serious illness and even death.

Oregon will be the 17th state to implement universal cystic fibrosis newborn screening. Several national organizations, including the March of Dimes, and the federal government have recommended that all

newborns be screened for cystic fibrosis.

Newborn screening is one of many public health programs within DHS that focus on prevention and helping people manage their health so they can be as productive and healthy as possible.

More information on newborn screening and specific disorders are on the Web at www.oregon.gov/DHS/ph/nbs/index.shtml

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