

## Screening for Infantile Krabbe disease

Krabbe disease is a severe inherited disorder that progressively damages an individual's brain and nerves. Symptoms of Krabbe disease can start at any age; but the disorder is the most severe when symptoms start shortly after birth. Babies affected with severe infantile Krabbe disease develop irritability, feeding problems, and stiff, jerky movements. The symptoms progress rapidly and affected babies become deaf, blind, and lose physical skills. Most affected babies die in their second year of life. There is no proven cure for infantile Krabbe disease; however, a bone marrow stem cell transplant may slow the disease if done before symptoms are present.

Ohio began screening for Krabbe disease in July 2016. It is one of many different disorders included as part of the Ohio Newborn Screening Panel. In order for a disorder to be part of the screening panel, there must be an accurate test using a very small blood sample, and a treatment must be available to improve the health of affected babies. The US Secretary of Health and Human Services has developed a list of disorders (called the RUSP – Recommended Universal Screening Panel) that every state should include in their newborn screening panel. Krabbe disease has not been added to the list of disorders on the national RUSP.

Because this rare disease is not currently recommended on the RUSP, the Ohio legislature has given parents the option to decline screening for Krabbe disease. Parents who do not want their baby screened for Krabbe disease must inform the nursing staff at the hospital that they decline Krabbe screening prior to the newborn screening test being performed. Only Krabbe screening can be declined by law, all other conditions included in the Ohio Newborn Screening Panel will be performed. Newborn screening results will be sent to the baby's doctor once testing is completed.

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