



# Krabbe Disease

Krabbe Disease is not included in the routine newborn screen (NBS) in Georgia. However, if you want your baby tested for Krabbe, there are resources available to help.

Krabbe is a serious disorder that can cause the protective layer around the nerve cells in the brain to weaken. Without this layer, the brain cannot work as it should.

Krabbe is very rare and only affects about 1 in 100,000 people in the United States. Doctors have had some success in treating Krabbe but treatment must begin as soon as possible.

Plans for screening must begin before the birth of the child. The test must be ordered by your child's doctor. The cost of Krabbe screening is the family's responsibility.

## **How to get Krabbe Screening**

If you choose to have your baby screened for Krabbe, your child's doctor can order the screening through any of the laboratories listed below:

**Hunter's Hope:**

[huntershope.org/newborn-screening](http://huntershope.org/newborn-screening)

**Perkin Elmer Genetics:**

[perkinelmer.com/genetics](http://perkinelmer.com/genetics)

**EGL Genetics:**

[egl-eurofins.com](http://egl-eurofins.com)

It is important that the Krabbe tests are collected within a few days of birth and sent immediately to the chosen lab. Talk with your child's doctor about who will collect the sample for Krabbe screening once your baby is born.

Results will be sent to your child's doctor. If the results are abnormal, the doctor should immediately contact the geneticist on call at Children's Healthcare of Atlanta.

If you have questions about Krabbe screening, please contact one of the following:

**NBS Short-term Follow-up Program:**

404.778.8560

**NBS Program Office:**

404.657.4143

**Georgia Public Health Laboratory:**

404.327.7900