

State of New Jersey
Department of Health and Senior Services
NOTICE OF AVAILABILITY OF
SUPPLEMENTAL NEWBORN SCREENING

New Jersey law mandates that every baby born in New Jersey be screened for 54 disorders that can cause serious health problems. These disorders may not be apparent at birth, but if left undetected and not treated early in life, can lead to problems that include mental retardation, disability, or even death.

The New Jersey Department of Health and Senior Services' Newborn Screening Program performs screening tests for these 54 disorders on all newborns within 48 hours after birth. The State laboratory uses an advanced technology, called tandem mass spectrometry (MS/MS), to test for these disorders. This technology may detect the presence of additional disorders for which screening is not mandated. If the State laboratory detects the presence of any disorder, the State will notify your health care provider.

New Jersey law requires health care providers to provide this pamphlet to expectant parents and guardians to advise you of the following. Supplemental newborn screening is available for other disorders in addition to the 54 disorders for which State law mandates screening. The State does not perform supplemental newborn screening. Private laboratories provide supplemental newborn screening. Supplemental newborn screening is optional. Your health care provider may recommend that supplemental newborn screening be performed. The cost for supplemental newborn screening is an out-of-pocket expense. The screening tests that private laboratories perform may repeat the tests for some or all of the 54 disorders for which the State already conducts screening.

If you decide to have supplemental newborn screening performed:

- Preferably several months in advance of your delivery date, you will need to purchase a supplemental screening test kit from a laboratory authorized by the Centers for Medicare and Medicaid Services (CMS).
- You will have to read and follow the instructions provided with the test kit, and tell your health care provider that you want supplemental screening.
- Typically, your health care provider will have to sign an order for the test, and the private laboratory will send the results to your health care provider.
- The State Newborn Screening Program will not receive the supplemental screening test results.

Reference in this notice to any specific commercial service, company, or organization does not constitute an endorsement or recommendation by the New Jersey Department of Health and Senior Services. The Department is not responsible for the content of any web page for which a link is provided below. If you have any questions, please contact your health care provider. Staff of the Department's Newborn Screening Follow-up Program and the Newborn Screening Laboratory, for whom contact information is given below, can provide you with information but cannot give medical advice and cannot advise as to whether to have supplemental newborn screening performed. This information is subject to change.

Informational Websites

Save Babies: www.savebabies.org
March of Dimes: www.marchofdimes.com
GeNeS-R-US: www.genes-r-us.uthscsa.edu
Gene Clinics: www.geneclinics.org

CMS Laboratory Information

www.cms.hhs.gov/clia
Phone: (877) 267-2323

Newborn Screening Follow-up Program

Lorraine Freed Garg, M.D., M.P.H.
E-mail: Lori.Garg@doh.state.nj.us
(609) 984-0755

Newborn Screening Laboratory

Scott M. Shone, Ph.D.
E-mail: Scott.Shone@doh.state.nj.us
(609) 341-5455

Acknowledgment of Receipt of Notice of Availability of Supplemental Newborn Screening

By signing this form, I confirm that:

- My health care provider gave me the pamphlet titled “New Jersey Department of Health and Senior Services Notice of Availability of Supplemental Newborn Screening” and I kept a hard copy of the pamphlet;
- My health care provider gave me a reasonable opportunity to read the pamphlet;
- I understand that mandatory newborn screening that the State will perform will not detect all possible disorders in infants for which tests are available;
- I understand that I am personally responsible for the cost of supplemental newborn screening; and
- I understand that if I choose to have supplemental newborn screening performed, then, several months in advance of the expected delivery date, I need to order the necessary kit from a laboratory of my choice and inform my health care provider that I want supplemental newborn screening performed.

Signature: _____

Print Name: _____

Date: _____

Relationship to Newborn (circle one):

Parent Guardian

Witness to Signature: _____

Print Name of Witness: _____

The health care provider shall maintain the signed original of this acknowledgement. The health care provider shall give the signer the pamphlet titled “New Jersey Department of Health and Senior Services Notice of Availability of Supplemental Newborn Screening.”