



CALIFORNIA NEWBORN SCREENING PROGRAM

Screening Your Newborn

*Important Information for Parents
About the Newborn Screening Test*



California Department of Public Health
Newborn Screening Branch
WWW.CDPH.CA.GOV/NBS



For more information about Newborn Screening,
visit our website at www.cdph.ca.gov/nbs



Congratulations!

The arrival of a new baby is an exciting time for a family. The California Newborn Screening (NBS) Program would like to take a few moments to tell you about newborn screening. Newborn screening can prevent serious health problems or even save your baby's life. Screening is the testing of a group of people to identify those who are at risk for having a specific disorder even though they may seem healthy. Newborn screening identifies most, but not all, of the babies who have one of the many disorders screened for by the California Program. Newborn Screening is a blood test that identifies babies with certain rare disorders so that treatment can be started right away.



.....

In California, about **1** out of every **600** babies tested will have one of these disorders. To ensure the health of all its newborns, state law requires that all babies born in California have the Newborn Screening Test.

.....

Why Should My Baby Be Tested?

Babies with any one of these disorders can look very healthy at birth and still have a serious disease, which is why your baby will be tested before leaving the hospital. By the time symptoms appear, it may be too late to prevent serious health problems to the baby.

Babies not born in hospitals must also have the NBS test. It should be done by the time your baby is 2 days old. Call your midwife or the baby's doctor to have your baby tested.





How Is The NBS Test Done?

A few drops of blood taken from the baby's heel are put on special filter paper. The blood is then sent to a state-approved lab for testing. The *ideal* time to do the test is when the baby is between 12 and 48 hours of age. This is a simple and safe test.

Before the test is collected, review the information on the pink copy of your baby's newborn screening test request form. Tell the provider if any of the information about you, your baby, or your baby's doctor is not correct. This will help make sure that your doctor gets your baby's newborn screening test results.

How Will I Know If The Test Has Been Done?

Your provider will give you the pink and blue copies of the test request form as proof that the test was done. Take the pink copy to your baby's first doctor visit.

If you move after the test is done, make sure you notify the hospital or midwife and your doctor's office with your new address and phone number. This will help us contact you and your doctor right away if your baby needs more tests.

NOTICE OF INFORMATION California Department Genetic Disease S The California Hea Effective

THIS NOTICE DESCRIBES HOW
ABOUT YOU OR YOUR NEWBO
HOW YOU CAN GET ACCESS TO
CAREFULLY.

Department's Legal Duty
Federal and State laws restrict the
and medical information obtained
to individuals whose information i

State laws include the California Bi
Government Code Section 11015
The federal law is the Health Infor
(49PPA), 42 USC 132062(a) (2)
Regulations Sections 160.100 et

Department Authority and Pur
The CDPH collects and maintain
124891, 125000, 125001, 1250
electronically and includes your
Code Section 132000) and req
quired information is not prop
ected newborns could retur

If you have religious objection
writing and sign a form advised
not responsible if your baby is
not identified and treated cor

Uses and Disclosure of the
The CDPH uses health inform
provides health care services
purposes, and to evaluate re
Some of this information is r
not be sold.

The law also allows the Dept
studies, such as research, re
with out any personal ident
ricular information if the
(PH) and meet all federal e

The Department is authori
recover all the experimen
retention, data processing
and related data manage
(continued on next page)

Parent's Copy

ADDRESSOGRAPH HERE

NEW FORM # 31 000 076 82 FORM 31 000 076 82

BIRTH INFORMATION	DATE OF BIRTH

DATE OF BIRTH

MOTHER'S BIRTH DATE

MOTHER'S BIRTH PLACE

MOTHER'S BIRTH DATE

MOTHER'S BIRTH PLACE

MOTHER'S BIRTH DATE

MOTHER'S BIRTH PLACE

MOTHER'S BIRTH DATE

MOTHER'S BIRTH PLACE

MOTHER'S BIRTH DATE

MOTHER'S BIRTH PLACE

MOTHER'S BIRTH DATE

MOTHER'S BIRTH PLACE

MOTHER'S BIRTH DATE

MOTHER'S BIRTH PLACE

MOTHER'S BIRTH DATE

MOTHER'S BIRTH PLACE

**CALIFORNIA NEWBORN SCREENING
TEST REQUEST FORM (TRF)
State of California -
Health and Human Services Agency**

FOR STATE USE ONLY

Why Do Some Babies Need More Tests?

There are two main reasons why more testing may be needed:

1

The lab could not run the test because there was a problem with the way the first blood sample was collected.

2

The test result was abnormal.

When more testing is needed, you will be contacted by your provider with instructions about what to do next. Make sure you follow their instructions and obtain the testing as soon as possible. If these disorders are not found and treated soon after birth, the baby can have serious and/or life-threatening health problems. Early treatment can prevent many of these problems.

How Much Does The Test Cost?

Please check with your provider or the Newborn Screening website at www.cdph.ca.gov/nbs for the current cost of the test. Medi-Cal, health plans and most private insurance will pay for the test.

How Can I Get The NBS Results?

You can request a copy from your baby's doctor or midwife. Your provider should receive your baby's results within a month.

If your provider does not have the results, he/she can contact the Newborn Screening Program to request a copy. Please provide your baby's doctor with the pink copy you were given after the test was collected. This will help your doctor get the results.

Can I Refuse The Test For My Baby?

You can refuse testing only if it is in conflict with your religious beliefs or practices. You must then sign a test refusal form. It states that not having the test done can result in serious illness or permanent damage to your child and that you accept responsibility should this occur.



What Types of Disorders Are Screened For In California?

Newborn screening identifies many rare, treatable genetic disorders. These disorders have varying degrees of severity.

If identified early, many of these conditions can be treated before they cause serious, sometimes life-threatening, health problems. Treatment may include close monitoring of the baby's health, medication, dietary supplements, and/or special diets.

Newborn screening identifies specific disorders in the following groups:

Metabolic Disorders

Metabolic disorders affect the body's ability to use certain parts of food for growth, energy, and repair. The parts include *amino acids* from proteins, *fatty acids* from fats and *organic acids* from proteins, fats, and sugars. Breakdown of these substances into usable forms happen with the help of enzymes and other proteins. When enzymes and other proteins are not available, some substances can build up and can be harmful to the body. Examples include phenylketonuria (PKU), galactosemia, and adrenoleukodystrophy (ALD).

Endocrine Disorders

Babies with endocrine disorders make too much or too little of certain hormones. Hormones are produced by glands in the body and affect body functions. Examples include primary congenital hypothyroidism (PCH) and congenital adrenal hyperplasia (CAH).

Hemoglobin Disorders

Hemoglobin is found in red blood cells. It gives blood its red color and carries oxygen to all parts of the body. Hemoglobin disorders often lead to anemia because they affect the type and amount of hemoglobin in the red blood cells. Examples include sickle cell anemia and hemoglobin H disease.

Newborn screening also identifies the following disorders:

Cystic Fibrosis (CF)

CF is a genetic disease that causes thick mucus to block small tubes and ducts in many systems of the body. This can lead to chronic infections, malnutrition and lung damage. Other organs, such as the liver and pancreas, may also be seriously affected. Early treatment can help decrease some of these problems.

Severe Combined Immunodeficiency (SCID)

This immune disorder is sometimes called “bubble boy” disease. Babies with SCID are born with little or no immune system. The immune system helps fight infections. Early treatment can help prevent life-threatening infections in babies with this disorder.

While newborn screening can identify some immune disorders, it does not test for HIV or AIDS in California.

The Newborn Screening Program evaluates adding other disorders to the screening panel as new tests and treatments become available. However, new-born screening does not test for every disorder that might be found. If there is a health concern or you know of a disorder that run in the family, talk to your doctor about what other tests can be done.



For a complete list of the diseases screened for by the NBS Program, please visit our website at www.cdph.ca.gov/programs/nbs/Documents/NBS-DisordersDetectable.pdf

What Happens To My Baby's Blood Spots After The Newborn Screening (NBS) Tests Are Done?

California, like many other states, stores residual NBS blood spots. After newborn screening has been completed, the filter paper cards with the residual blood spots are labeled with a unique bar code. The Newborn Screening Program does not store information about your baby's entire DNA or store your baby's "DNA profile." The state does not have a DNA database from the specimens collected.



If you have additional questions about the use of stored blood spots, please visit our website at www.cdph.ca.gov/programs/nbs/Pages/NBSDBS-Storage.aspx email us at CaliforniaBiobank@cdph.ca.gov



What are the stored bloodspots used for?

The NBS Program uses residual blood spots for:

- quality control testing to ensure the tests are correct and the lab equipment is working
- to evaluate and improve the current NBS program
- to develop new tests to add to the panel, such as when cystic fibrosis was added

Over the last 20 years, newborn screening in California has gone from testing each baby for 3 diseases to testing for over 75 disorders. By adding tests, we have been able to prevent serious illness, including death and disability, in many more babies.

Are the stored blood spots used for anything else?

Yes. California law requires the NBS program to use or provide newborn screening specimens for department-approved studies of diseases in women and children, such as research related to identify-ing and preventing disease. This could be to study birth defects, chronic disease, exposure to toxins or infections. There are several levels of oversight in place to ensure that uses are appropriate. Researchers must meet all federal and state privacy law requirements. The blood spots are provided without any personal identifying information. Because of this, you will not be notified of any study test results for your baby. No extra blood spots or specimens will be collected from your baby for research.



Could the stored blood spots ever benefit me or my baby?

Yes. The stored NBS blood spots could provide useful information to you or your family. In the future, the blood spot could be used, with your permission, to detect a disorder not included in the NBS panel.

You may request that your child's sample be sent to a specific research study, your baby's doctor, or a laboratory for testing not done by the NBS Program.

Can I request that my baby's blood spots be destroyed?

You may request your baby's blood spots be destroyed after newborn screening has been completed. Keep in mind that if your baby's blood spots are destroyed, they will not be available if you need them in the future. To get a form to request that your child's blood spots be destroyed, go to:



[www.cdph.ca.gov/programs/GDSP/
Pages/ParentForms.aspx](http://www.cdph.ca.gov/programs/GDSP/Pages/ParentForms.aspx)





Americans with Disabilities Act (ADA)

Notice of Information and Access Statement
Policy of Nondiscrimination on the Basis of Disability and
Equal Employment Opportunity Statement

The California Department of Public Health (CDPH) complies with all state and federal laws, which prohibit discrimination in employment and provide admission to its programs or activities.

The Deputy Director, Office of Civil Rights (OCR), CDPH has been designated to coordinate and carry out the department's compliance with nondiscrimination requirements. Title II of the ADA addresses nondiscrimination and access issues regarding disabilities. To obtain information concerning the CDPH EEO Policies or the provision of the ADA and the rights provided, you may contact the CDPH OCR by phone at 916-440-7370, TTY 916-440-7399 or write to:

OCR, CA Department of Public Health, P.O.
Box 997413, MS 0009,
Sacramento, CA 95899-7413

Upon request, this document will be made available in Braille, high contrast, large print, audiocassette or electronic format. To obtain a copy in one of these alternate formats, call or write:

Chief, Newborn Screening Branch
850 Marina Bay Pkwy., F175, MS 8200
Richmond, CA 94804
Phone: 510-412-1502 | Relay Operator: 711/1-800-735-2929

