

NOTICE OF INFORMATION AND PRIVACY PRACTICES
California Department of Public Health (CDPH)
Genetic Disease Screening Program
Newborn Screening Branch
(Effective August 2008)

Please Review Carefully

This notice describes how personal and medical information about you or your newborn may be used and disclosed and how you can get access to this information.

Department's Legal Duty

Federal and State laws restrict the use, maintenance, and disclosure of personal and medical information obtained by a State agency and requires certain notices to individuals whose information is maintained. In compliance with these laws, you and those providing information are notified of the following:

Department Authority and Purpose for the Newborn Screening Program

The CDPH collects information related to newborn screening as permitted in Health and Safety Code Sections 124980, 125000, 125001, 125025, and 125030. This information is collected electronically and includes such things as your name, address, medical care given to you and your newborn. Testing is required by law (Health and Safety Code Section 125000) and regulations (17 CCR 6500 through 6510) and if the required information is not provided, serious illness or permanent damage for affected newborns could result.

If you have religious objections to this testing, you may say "no" to the testing in writing and sign a form advising you that your hospital, doctor, and clinic staff are not responsible if your baby develops problems because those disorders were not identified and treated early.

Uses and Disclosure of Health Information

The CDPH uses health information about you or your newborn for screening, to provide health care services, to obtain payment for screening, for administrative purposes, and to evaluate the quality of care that you or your newborn receives. Some of this information is retained for as long as 21 years. The information will not be sold.

The law also allows the Department to use or give out information we have about you or your newborn for the following reasons:

- For research studies unless you specifically request in writing that your information or specimen not be used.
- To organizations, which help us in our operations, such as collecting fees.

The Department may change its policies at any time subject to applicable laws and regulations. You may request a copy of our current policies or obtain more information about our privacy practices by contacting the Chief of the Genetic Disease Screening Program at 850 Marina Bay Parkway, F175, Richmond, CA 94804 or consulting our website at www.cdph.ca.gov/programs/pages/privacyoffice.aspx.

Individual Rights and Access to Information

The Newborn Screening Program must have your written permission to use or give out personal or health information about you for any reason that is not described in this notice. You can revoke your authorization at any time, except if the Newborn Screening Program has already acted because of your permission by contacting the Chief of the Genetic Disease Screening Program at 850 Marina Bay Parkway, F175, Richmond, CA 94804.

You have the right to look at or receive a copy (you will be charged) of your or your newborn's health information and receive a list of instances where we have disclosed health information about you or your newborn for reasons other than screening, payment or related administrative purposes.

You have a right to have information in your or your child's records changed if information is missing or you believe the information is incorrect. If the information you want to change did not come from Newborn Screening Program, we may not be able to change it, but we will keep a copy of your request with our records.

You have a right to ask that Newborn Screening Program contact you only in writing or at a different address, post office box, or telephone number. Newborn Screening Program will contact you the way you have asked if this is necessary to keep you safe.

You have a right to ask Newborn Screening Program not to use or share your or your newborn's information in the ways listed in this notice. However, we may not be able to comply with your request.

Newborn Screening Program may not retaliate or refuse to pay your bills in any way if you choose to file a complaint or use any of your privacy rights in this notice.

The information on this form is maintained by the California Department of Public Health, Genetic Disease Screening Program. Please address correspondence to the Chief of the Genetic Disease Screening Program, 850 Marina Bay Parkway, F175, Mail Stop 8200, Richmond, California, 94804 (510-412-1502).

Attention Parents:

- 1) Review the information on the pink copy of your baby's newborn screening test request form. Notify the hospital if your name, address, and/or phone or the name, address and phone number of your baby's doctor is not correct.
- 2) Take the pink copy of this form when you go to your baby's first check up. This will help the doctor locate your baby's newborn screening results.

Copies and Other Languages

To get a copy of this notice in other languages, Braille, large print, audiocassette or computer disk, please call or write the Privacy Officer at the address and number listed below.

Important: Newborn Screening Program does not have complete copies of your health records. If you want to look at, get a copy of, or change your health records, please contact your doctor, clinic, or health plan.

Notices

This privacy notice is from the Newborn Screening Program. You may get other privacy notices from your doctor and other health care programs.

How Do You Use Your Rights

If you believe that we have not protected your or your newborn's privacy or have violated any of your or your newborn's rights you may file a complaint by calling or writing: Privacy Officer, California Department of Public Health, P.O. Box 997377, Sacramento, CA 95899-7377, 916-440-7671 or 877-421-9634 TTY/TDD. Or visit our website at: www.cdph.ca.gov/program/Pages/PrivacyOffice.aspx

Or

You may also contact the Regional Manager, Department of Health and Human Services, Office for Civil Rights at 90 7th Street, Suite 4-100, San Francisco, CA, 94103, telephone 800-368-1019 or U.S. Office for Civil Rights at 866-OCR-PRIV (866-627-7748) or 866-788-4989 TTY.