

NOTICE OF INFORMATION AND PRIVACY PRACTICES
California Department of Public Health (CDPH)
Genetic Disease Screening Program (GDSP)
The California Newborn Screening Program
Effective Date: June 2014

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. PLEASE REVIEW IT CAREFULLY.

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.

State laws include the California Information Practices Act (Civil Code 1798 et seq.), Government Code Section 11015.5 and Health and Safety Code Section 124980. The federal law is the Health Insurance Portability and Accountability Act of 1996 (HIPAA), 42 USC 1320d-2(a) (2), and its regulations in Title 45 Code of Federal Regulations Sections 160.100 et seq. 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 and maintains specimens and information related to newborn screening as permitted in Health and Safety Code Sections 124980, 124977, 124991, 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 newborn screening specimens and/or general health information about you or your baby, for department-approved studies, such as research related to preventing disease. The material will be provided, **without any personal identifying information**. Researchers can only apply to receive the information if they have been approved by an institutional review board (IRB) and meet all federal and state privacy law requirements.

The Department is authorized by law to charge approved researchers a fee to recover all the expenses related to the research request (including data linkage, retrieval, data processing, data entry, re-inventory, shipping of blood samples, and related data management).

The Department reserves the right to change the terms of this notice and to make the new notice provisions effective for all protected health information that it maintains. The most current Privacy Notice can be found at the Newborn Screening Program website: www.cdph.ca.gov/programs/nbs. You may request a copy of the current policies or obtain more information about our privacy practices, by calling the numbers listed below or consulting the Program website. You may also request a paper copy of this Notice. This Privacy Notice can also be found at the website: www.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 ask that the 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 the Newborn Screening Program not to use or share your or your newborn's information and/or specimen in the ways listed in this notice. However, we may not be able to comply with your request.

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.

Complaints

We will let you know promptly if a breach occurs that may have compromised the privacy or security of your information. If you believe that we have not protected your privacy or have violated any of your rights and wish to file a complaint, please call or write to the: Privacy Officer, CA Department of Public Health, P.O. Box 997377, MS 0506, Sacramento, CA 95899-7377, (916) 440-7671 or (877) 421-9634 TTY/TDD.

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

The Department cannot take away your health care benefits or any other protected rights in any way if you choose to file a complaint or use any of the privacy rights in this notice.

Department Contact-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).

Electronic Copies of this Notice: To get a copy of this notice in an electronic format call or write to:

Chief, Genetic Disease Screening Program
850 Marina Bay Pkwy, F175, Mail Stop 8200, Richmond, CA 94804
Phone: 510-412-1502 Relay Operator 711/1-800-735-2929