

NOTICE OF INFORMATION PRACTICES AND PRIVACY PRACTICES  
CALIFORNIA DEPARTMENT OF PUBLIC HEALTH  
GENETIC DISEASE SCREENING PROGRAM,  
THE CALIFORNIA PRENATAL SCREENING PROGRAM  
EFFECTIVE DATE: NOVEMBER, 2008

This notice describes how personal (including medical) information about you may be used and disclosed, and how you 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 (including medical) information obtained by a State agency, and require 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 Prenatal Screening Program.** The Department of Public Health collects and uses personal and medical information as permitted in Health and Safety Code Sections 124977, 124980, 125000, 125002, 125050, 125055, and 123055, and according to procedures in State regulations (17 CCR 6527, 6529, 6531 and 6532). It is used to estimate the risk of serious birth defects in the pregnancy and provide diagnostic testing for pregnant women.

If not provided, problems could result such as not detecting an affected fetus, falsely reporting increased risk causing unnecessary invasive testing, or not being able to bill properly for the services provided. This information is collected electronically and includes such things as your name, address, testing results, and medical care given to you.

**Uses and Disclosure of Health Information.** The Department of Public Health uses health information about you for screening, to provide health care services, to obtain payment for screening, for administrative purposes, and to evaluate the quality of care that you receive. 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 for the following reasons:

- \* For research studies, that have been approved by an institutional review board and meet all federal and state privacy law requirements, such as research related to preventing disease.
- \* For medical research without identification of the person from whom the information was obtained, unless you specifically request in writing that your information not be used, **by writing to the address** listed below.
- \* To organizations which help us in our operations, such as by collecting fees. If we provide them with information, we will make sure that they protect the privacy of information we share with them as required by Federal and State law.

The **Genetic Disease Program must have your written permission to use or give out personal and 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 Genetic Disease 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.

The Department may change its policies at any time subject to applicable laws and regulations. If it does so, we will notify you and you may request a copy of our current policies or obtain more information about our privacy practices, by **calling the numbers** listed below or consulting our website at [www.cdph.ca.gov](http://www.cdph.ca.gov). You may also request a paper copy of this Notice. **This Privacy Notice can be found on our website at: [www.ca.gov/programs/pages/Privacyoffice.aspx](http://www.ca.gov/programs/pages/Privacyoffice.aspx).**

**Individual Rights and Access to Information.** You have the right to look at or receive a copy of your health information. If you request copies, we will charge you \$0.10 (10 cents) for each page. You also have the right to receive a list of instances where we have disclosed health information about you for reasons other than screening, payment or related administrative purposes. If you believe that information in your record is incorrect or if important information is missing, you have the right to request that we correct the existing information or add the missing information. You have the right to ask us to contact you at a different address, post office box or telephone number. We will accept reasonable requests.

You may request in writing that we restrict disclosure of your information for health care treatment, payment and administrative purposes, **however we** may not be able to **comply** with your request.

**Complaints.** 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** – (Who Maintains the Information). The information on this form is maintained by the Department of Public Health, Genetic Disease Screening Program. The Chief of the Genetic Disease Screening Program may be reached at 850 Marina Bay Parkway, F175, Richmond, California, 94804, (510) 412-1500. The Chief is responsible for the system of records and shall, upon request, inform you about the location of your records and respond to any requests you may have about information in those records.

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 and access 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 provisions 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 Dept. of Public Health  
MS0009, P.O. Box 997413  
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, Prenatal Screening Branch  
850 Marina Bay Pkwy, F175, Mail Stop 8200, Richmond, CA 94804  
Phone: 510-412-1502 Relay Operator 711/1-800-735-2929