

NOTICE OF INFORMATION PRACTICES AND PRIVACY PRACTICES
CALIFORNIA DEPARTMENT OF PUBLIC HEALTH GENETIC DISEASE
SCREENING PROGRAM PRENATAL AND NEWBORN SCREENING BRANCHES
EFFECTIVE DATE APRIL 14, 2003

THIS NOTICE DESCRIBES HOW PERSONAL (INCLUDING 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 (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 Section 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 personal and medical information as permitted in Health and Safety Code Sections 124997, 124980, 125000, 125050, 125055, 123055. The information is collected and used according to procedures in State regulations (15CCR 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.

Department Authority and Purpose for the Newborn Screening Program. The Department of Public Health 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. This information is used to identify newborns with inherited or congenital disorders in order to prevent or provide treatment for the disorder. 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, death or permanent handicaps for affected newborns could result. If you have religious objections to testing, you may say "no" to 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 Department of Public Health 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 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 contacting the person listed below
- To organizations, which help us in our operations, such as by collecting fees. If we do, we will make sure that they protect the privacy of information we share with them as required by federal and state law.

The information is otherwise confidential and will not be released without your written authorization. If you choose to sign an authorization to disclose information you can later revoke that authorization to stop any future uses and disclosures by contacting the person listed below.

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 contacting the person listed below or consulting our website at http://www.cdph.ca.gov/programs/GDSP/Pages/PDE_Branch.aspx.

You may also request a paper copy of this Notice.

Individual Rights and Access to Information. You have the right to look at or receive a copy of your or your newborn's 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 or your newborn for reasons other than screening, payment or related administrative purposes. If you believe that information in your or your newborn's 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 only in writing or 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 or your newborn's information for health care treatment, payment and administrative purposes. We are not required to agree to your request.

Complaints. 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 and wish to complain, please call or write us at:

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 file a complaint by calling or writing the **Privacy Officer**, CA Department of Health Services, at the address and telephone number above. You may also contact the Secretary of the Department of Health and Human Services, Office for Civil Rights at 50 United Nations Plaza, Room 322, San Francisco, CA. 94102, telephone (800) 368-1019. Or you may call the U.S. Office for Civil Rights at 866-OCR-PRIV (866-627-7748) or 866-788-4989 TTY.

The Department cannot take away your health care benefits or do anything to hurt you 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 Acting Chief of the Genetic Disease Screening Program is Fred Lorey PhD., 850 Marina Bay Parkway, Room F-175, Richmond, California, 94804 (510-412-1490). He 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.