

The California Prenatal Screening Program

Sequential Integrated Screening

First and second trimester blood test results
combined with Nuchal Translucency

Serum Integrated Screening

Combines first trimester blood test results
with second trimester blood test results



Quad Marker Screening

One blood specimen drawn second trimester
(15 weeks-20 weeks)

The California Prenatal Screening Program is voluntary. Women can refuse testing without losing insurance benefits or eligibility or services from State Programs.

California law prohibits the use of test results by insurance companies or employers to discriminate against an individual. If you believe that you have experienced discrimination as a result of prenatal screening, write to Chief of the Genetic Disease Screening Program, at the address below.

California Department of Public Health
Genetic Disease Screening Program
850 Marina Bay Parkway, F175
Richmond, CA 94804
866-718-7915 toll free



For more information visit our website: www.cdph.ca.gov or email us: pns@cdph.ca.gov

March 2017

The California Prenatal Screening Program

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The California Prenatal Screening Program

Checking a Baby's Health Before Birth

During pregnancy, it is important to know as much as possible about the health of the developing baby. For some women, this means testing for birth defects. Babies can be born with birth defects even when the mother is healthy. The California Prenatal Screening Program can help detect some birth defects such as:



- Down syndrome.....a cause of intellectual disability
- Trisomy 18.....intellectual disability and severe physical birth defects
- Trisomy 13.....intellectual disability and severe physical birth defects
- Neural tube defects.....such as spina bifida (open spine)
- Abdominal wall defects.....the baby's intestines are outside the body
- Smith-Lemli-Opitz syndromeSLOS is a very rare condition causing intellectual disability and physical birth defects

A screening test estimates the chance (risk) that the baby has certain birth defects. This is called a "Risk Assessment". If the risk is high, a woman may then choose to have advanced screening or diagnostic tests that confirm or rule out most birth defects.

See pages 9-10 for a description of these birth defects

REMEMBER, it is a woman's decision whether to have prenatal screening tests. A Consent or Decline form is on pages 14-17.

Blood Tests are Part of Prenatal Screening

A small amount of blood is taken from the pregnant woman's arm and sent to the Program. At different times during pregnancy, her blood is tested for substances such as:

- PAPP-APregnancy Associated Plasma Protein A
- hCG.....Human Chorionic Gonadotropin
- AFPAlpha-Fetoprotein
- uE3Unconjugated Estriol
- Inhibin.....Dimeric Inhibin-A (DIA)

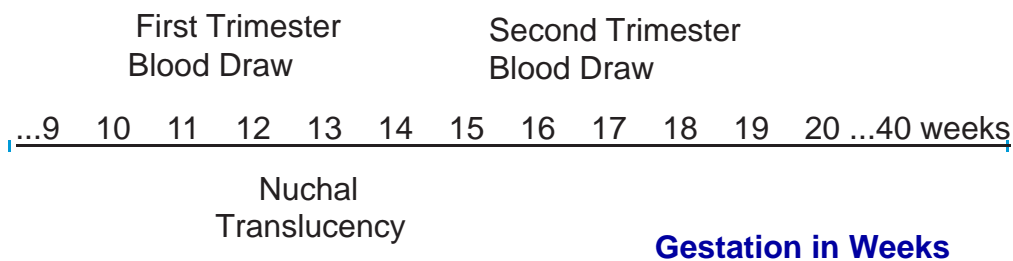
These substances are made by the pregnant woman and her unborn baby. At each week of pregnancy, there are different expected amounts of these substances in the mother's blood. Other information used for the screening test includes age, race and weight.

Blood test results are sent to a woman's doctor or clinic 7 to 10 days after blood draw.



Based on her week of pregnancy, a woman and her doctor can choose which type of screening is best for her.

Screening Timeline



The California Prenatal Screening Program Offers Three Types of Screening Tests

Sequential Integrated Screening

First Trimester Risk Assessment

A first trimester blood specimen is drawn at 10 weeks 0 days – 13 weeks 6 days of pregnancy. A Nuchal Translucency* (NT) ultrasound is done between 11 weeks 2 days and 14 weeks 2 days of pregnancy. A preliminary risk assessment is provided for Down syndrome and Trisomy 18.

Second Trimester Risk Assessment

A second trimester blood specimen is drawn at 15 weeks 0 days – 20 weeks 0 days of pregnancy. These test results are combined with the first trimester test results and NT ultrasound. New risk assessment is provided for Down syndrome and Trisomy 18. Risk assessment is also provided for neural tube defects and SLOS.

Serum Integrated Screening (No NT ultrasound)

A first trimester blood specimen is drawn at 10 weeks 0 days – 13 weeks 6 days of pregnancy. A second trimester blood test is drawn at 15 weeks – 20 weeks. The results of the two blood tests are combined. Risk assessment is reported, only in the second trimester, for Down syndrome, Trisomy 18, neural tube defects and SLOS.

Quad Marker Screening

One blood specimen is drawn at 15 weeks – 20 weeks of pregnancy (second trimester). Risk assessment is reported in the second trimester for Down syndrome, Trisomy 18, neural tube defects and SLOS.

***Nuchal Translucency (NT)** - A type of ultrasound done only by doctors or technicians with special training. It measures the fluid at the back of the baby's neck. All babies have a collection of fluid, but babies with Down syndrome and Trisomy 18 tend to have more.

You should talk to your doctor about where to go for Nuchal Translucency Ultrasound. Also talk to your insurance about coverage. This special ultrasound is not provided by the Prenatal Screening Program.

Comparing The Three Types of Prenatal Screening Tests

Name of Screening Test	Test Type	When the Test is Done	Detection Rates
Sequential Integrated Screening	Two Blood Draws + Nuchal Translucency Ultrasound	First blood draw between 10 weeks to 13 weeks 6 days of pregnancy. Nuchal Translucency ultrasound 11 weeks 2 days to 14 weeks 2 days Second blood draw between 15 to 20 weeks of pregnancy.	90 out of 100 Down syndrome 81 out of 100 Trisomy 18 97 out of 100 anencephaly 80 out of 100 open spina bifida 85 out of 100 abdominal wall defects 60 out of 100 SLOS
Serum Integrated Screening	Two Blood Draws	First blood draw between 10 weeks to 13 weeks 6 days of pregnancy. Second blood draw between 15 to 20 weeks of pregnancy.	85 out of 100 Down syndrome 79 out of 100 Trisomy 18 97 out of 100 anencephaly 80 out of 100 open spina bifida 85 out of 100 abdominal wall defects 60 out of 100 SLOS
Quad Marker Screening	One Blood Draw	Between 15 to 20 weeks of pregnancy	80 out of 100 Down syndrome 67 out of 100 Trisomy 18 97 out of 100 anencephaly 80 out of 100 open spina bifida 85 out of 100 abdominal wall defects 60 out of 100 SLOS

Based on your week of pregnancy, you and your doctor can choose which type of screening is best for you

The Types of Screening Results

Your results are specific to you and your current pregnancy.

Result: Preliminary Risk Assessment - This first trimester result means that the risk (chance) of the baby having Down syndrome or Trisomy 18 is low.... low enough that the Program does not offer follow-up tests.

Result: Screen Negative - This second trimester result means that the risk (chance) of the baby having any of the screened birth defects is low.... low enough that the Program does not offer follow-up tests.

Important: A result of **Screen Negative** or **Preliminary Risk Assessment** does not guarantee that there are no birth defects. Prenatal Screening tests **cannot** detect 100% of these birth defects.

See Chart on page 5 to compare detection rates of the three types of prenatal screening tests.

Result: Screen Positive - This means that the risk (chance) of the baby having any of these birth defects is higher than usual. The Program offers follow-up tests to look for possible birth defects.

Important: A result of **Screen Positive** does not always mean that there is a birth defect.

Most women with a screen positive result will have normal follow-up diagnostic tests and healthy babies.

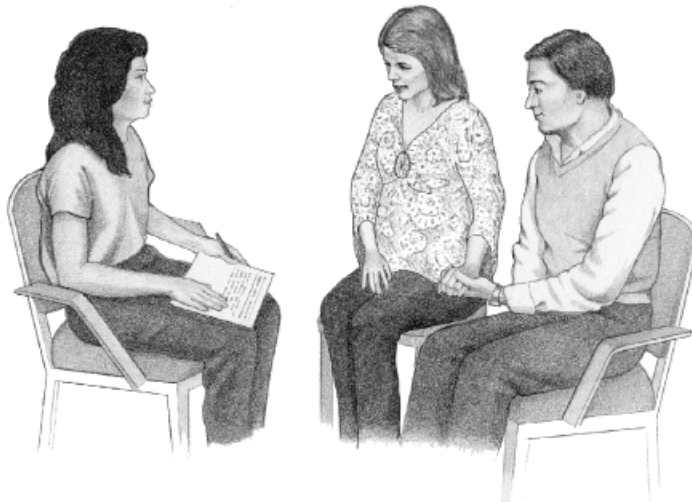
Test Results and Follow-Up Services

If any test is *Screen Positive*, what happens next?

A woman with a Screen Positive result will be called by her doctor or clinic. She will be offered follow up services at a State-approved Prenatal Diagnosis Center up to 24 weeks of pregnancy. Authorized services are free at a State-approved Prenatal Diagnosis Center.

A woman can decline services at any time. She can accept some services such as genetic counseling, and decline other services at the Prenatal Diagnosis Center.

◆ **Genetic Counseling:** The first service a woman receives at the Prenatal Diagnosis Center is **genetic counseling**. A Genetic Counselor explains the test results and reviews the family medical history. The counselor explains the follow-up tests which may be offered.



A Genetic Counselor helps a woman decide whether to have diagnostic testing.

Tests Which May be Offered After Genetic Counseling:

◆ **Prenatal Cell-free DNA (cfDNA) Screening:**

This is a blood test using fetal DNA that is found in the mother's blood. Prenatal cfDNA screening is considered to be a very accurate screening test for certain chromosome abnormalities like Down syndrome and Trisomy 18. This test is offered at 10 weeks - 24 weeks of pregnancy.

◆ **CVS** (Chorionic Villus Sampling): This may be offered at 10-14 weeks of pregnancy. An experienced State-approved doctor takes a small number of cells from the placenta. These cells are tested for Down syndrome, Trisomy 18, and other chromosome abnormalities.

◆ **Ultrasound:** A detailed picture of the baby is made using sound waves. After 15 weeks of pregnancy, a doctor examines the baby very closely for birth defects.

◆ **Amniocentesis:** This may be offered after 15 weeks of pregnancy. An experienced State-approved doctor takes a small amount of fluid from around the baby. Tests are done for specific birth defects and for Down syndrome, Trisomy 18 and other chromosome abnormalities.

Birth Defects Found Through Diagnostic Testing

Down Syndrome

Down syndrome is caused by an extra chromosome #21 (Trisomy 21). Chromosomes are packages of genetic material found in every cell of the body. Birth defects can occur when there are too few or too many chromosomes.

Down syndrome is a common cause of intellectual disability and birth defects. Down syndrome can affect babies born to women of any age. However, as women get older, the chances increase for having a baby with Down Syndrome.

Trisomy 18

Trisomy 18 is caused by an extra chromosome #18. Most babies with Trisomy 18 are lost through miscarriage. Babies born with Trisomy 18 have intellectual disability and physical defects.

Trisomy 13

Trisomy 13 is caused by an extra chromosome #13. Most babies with Trisomy 13 are lost through miscarriage. Babies born with Trisomy 13 have intellectual disability and severe physical birth defects.

Smith-Lemli-Opitz Syndrome (SLOS), SCD

This is a very rare birth defect. Babies born with Smith-Lemli-Opitz syndrome (**SLOS**) cannot make cholesterol normally. Babies born with this condition have intellectual disability and may have many physical defects.

Screen Positive results for SLOS can also indicate increased chances for Congenital abnormalities and fetal **Demise** (fetal death). That is why this screening is also called **SCD** screening.

Neural Tube Defects (NTD)

As a baby is forming, the neural tube extends from the top of the head to the end of the spine. This develops into the baby's brain and spinal cord. The neural tube is completely formed by 5 weeks after conception.



When there is an opening in the spine, it is called **spina bifida**. This defect often causes paralysis of the baby's legs. It may also cause loss of bowel and bladder control.

Anencephaly occurs when most of the brain does not develop. This defect causes the death of the baby or newborn.

Abdominal Wall Defects

Abdominal Wall Defects (**AWD**) are problems involving the baby's abdomen and intestines. These defects happen when the intestines and other organs are outside the body. Surgery after birth is usually performed to correct the defect.

What if diagnostic tests show that the baby has a birth defect?

Information will be given to the woman by a doctor or genetic counselor at the Prenatal Diagnosis Center. They will discuss the birth defect, and options for the pregnancy. The Program does not pay for any other medical services after the diagnostic tests. Referrals for special support services for special needs babies are available.

There are other birth defects which cannot be detected by the Program.

Diagnostic Tests Instead of Screening Tests for Birth Defects

Some women may consider diagnostic tests **instead of** screening tests. **A diagnostic test** can tell whether or not the baby actually has a specific birth defect. **Screening** estimates the risk of certain birth defects.

Diagnostic tests during pregnancy can include **amniocentesis** or **chorionic villus sampling** (CVS). Diagnostic tests done instead of screening tests are not covered by the Program.

Who may want to consider diagnostic testing instead of screening?

- ◆ women with a medical or family history of inherited conditions
- ◆ women who know that the baby's father has a medical or family history of inherited conditions
- ◆ women who are taking certain medicines
- ◆ women who have diabetes prior to pregnancy
- ◆ women with other high risk pregnancies
- ◆ women age 35 and older at delivery

Before deciding between a screening test and a diagnostic test, you should talk to your doctor or a genetic counselor. Some insurance policies may cover genetic counseling. Ask your doctor for the pamphlet "Prenatal Diagnosis".



Program Fee

What is the fee for the Prenatal Screening Program?

Presently, the fee is \$221.60. Check with your doctor or clinic about the current fee. **The fee covers the blood tests and authorized follow-up services at a State-approved Prenatal Diagnosis Center.**

The Program charges \$221.60 when:

- ◆ there is one blood test or two
- ◆ there is one baby or two.



The Program fee *does not* cover:

- ◆ blood draw charges
- ◆ nuchal translucency ultrasound

The Program mails a bill and insurance form to the patient unless insurance information is received with the blood specimen. In most cases, health insurance companies and HMOs are required to cover the fees for the screening program after any deductible or co-pay. There is an exception made for self-insured employers. Medi-Cal covers the Program fee.

Contact your health insurance provider to determine your plan's payment or co-pay for prenatal testing.

Consent

Please talk to your doctor about the screening tests described in this booklet. If you decide to participate in Prenatal Screening, you do not need to consent to any specific type of blood screening test. You only need to consent to participate in the Prenatal Screening Program. Or, you can decline to participate in the Program.

To document either choice, you will need to sign the **Consent or Decline form** on the next page.

Research

The California Birth Defects Monitoring Program was created to collect information on birth defects. This Program helps researchers to identify the causes of birth defects and other health problems of women and children.

The Birth Defects Monitoring Program and the Prenatal Screening Program are both part of the California Department of Public Health. After screening is completed, the Prenatal Screening Program saves some blood specimens and stores them with the Birth Defects Monitoring Program.

The Department of Public Health must approve any research and any use of these specimens by the Birth Defects Monitoring Program. The Department maintains your confidentiality under the laws and regulations that apply.

The prenatal screening specimens are valuable for research about the causes and prevention of birth defects. However, you can have prenatal screening and decline the use of your specimen for research through a check box on the consent form. Declining research will not affect your health care or test results in any way.

**CLINICIAN COPY
MUST BE FILED IN PATIENT CHART**

**Consent or Decline
California Prenatal Screening Program**

1. I have read the information in this booklet (or have had it read to me).
2. I understand that:
 - a. The Prenatal Screening Program offers prenatal tests for the detection of birth defects such as Down syndrome, Trisomy 18, Trisomy 13, Smith-Lemli-Opitz syndrome (SLOS), Neural Tube Defects, and Abdominal Wall Defects. These birth defects cannot be detected 100 % of the time.
 - b. There is a Program fee charged to the patient. This fee may be covered by health insurance. I agree to pay any part of this fee not covered by insurance.
 - c. If the blood test result is Screen Negative, the Program will not pay for any follow-up testing.
 - d. If the blood test result is Screen Positive, I will need to make a decision regarding follow-up diagnostic testing.
 - e. If the baby is found to have a birth defect, the decision to continue or terminate the pregnancy is entirely mine.
 - f. There are birth defects that cannot be detected with screening tests.
3. I also understand that:
 - a. Participation in the Prenatal Screening Program is voluntary. I can decline any test at any time.
 - b. Consent to participate in the Program may include Quad, Serum or Sequential Integrated Screening.

<p>Yes</p> <p>I Consent to Screening</p>	<p>I consent to participate in the California Prenatal Screening Program. I request that blood be drawn for Prenatal Screening.</p> <p>I agree that my blood specimen may be used for research by the Department of Public Health, or Department approved researchers, unless I mark the box below.</p> <p><input type="checkbox"/> I decline the use of my specimen for research.</p> <p>The Department will maintain confidentiality according to applicable laws and regulations.</p> <p>Signed _____ Date _____</p>
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<p>No</p> <p>I Decline Screening</p>	<p>I decline to participate in the California Prenatal Screening Program. I request that blood not be drawn for Prenatal Screening.</p> <p>Signed _____ Date _____</p>
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PATIENT COPY

**Consent or Decline
California Prenatal Screening Program**

1. I have read the information in this booklet (or have had it read to me).
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<p>No</p> <p>I Decline Screening</p>	<p>I decline to participate in the California Prenatal Screening Program. I request that blood not be drawn for Prenatal Screening.</p> <p>Signed _____ Date _____</p>
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Environmental Health Information

Reproductive Health and the Environment

We encounter chemicals and other substances in everyday life that may affect your developing baby. Fortunately, there are steps you can take to reduce your exposure to these potentially harmful substances at home, in the workplace, and in the environment. Many Californians are unaware that a number of everyday consumer products may pose potential harm. Prospective parents should talk to their doctor and are encouraged to read more about this topic to learn about simple actions to promote a healthy pregnancy.

At the University of California, San Francisco, the Program on Reproductive Health and the Environment produces ***All That Matters*** brochures. These are nontechnical, patient-centered guides that provide tips and suggestions for avoiding toxic chemical exposure at home, in the workplace and in the community. These resources include:

- Toxic Matters – Provides tips on avoiding chemicals for pregnant women and women who want to become pregnant.
- Cuestiones de Salud – a Spanish language edition of Toxic Matters.
- Work Matters – Explains how to prevent toxic exposures in the work place, and how pregnant women can secure their rights to a safe and healthy work environment.
- Food Matters: What to Eat? – Explains how to select foods with lower exposure to toxic chemicals.
- Pesticides Matter – Provides tips on avoiding exposure to pesticides at work and at home and how to protect one's family.

The All That Matters brochures are available online at:

<http://prhe.ucsf.edu/prhe/allthatmatters.html>

For a more detailed resource, the American Academy of Pediatrics produces **Pediatric Environmental Health**. This book provides comprehensive information on a wide range of environmental health issues.

Information About Cord Blood Banking

As a pregnant woman gets closer to her delivery date, the option of saving the baby's cord blood can be considered. Newborn umbilical cord blood contains stem cells which may be used to treat people with certain blood-related disorders. These include some types of cancer, immune system disorders, and genetic diseases.

Newborn cord blood can be collected from the umbilical cord shortly after birth. This does not interfere with the birthing process. It does not harm the health of either the baby or the mother. The collection of cord blood is safe, quick, and painless. If not collected, cord blood is discarded as medical waste.

Parents may choose to have their newborn's umbilical cord blood donated to a public cord blood bank. This donated cord blood can be made available to anyone who may need a blood stem cell transplant. It may also be made available to researchers who are trying to discover the causes of birth defects and other health-related problems. There is no cost for publicly donating cord blood.

Parents may instead choose to store their newborn's umbilical cord blood at a private cord blood bank. This cord blood could possibly be used if a compatible family member requires a blood stem cell transplant. There are fees for collecting and storing cord blood at a private cord blood bank.

Both private and public cord blood banks are available in California. Parents interested in donating their baby's cord blood should talk with their prenatal care provider by the 34th week of pregnancy, or earlier.

For more information on both public and private cord blood banking, visit or call:

- ◆ National Cord Blood Program:
www.nationalcordbloodprogram.org; 866-767-6227
- ◆ National Marrow Donor Program:
www.bethematch.org; 800-627-7692

Attachment 10 - California Prenatal Screening Program

NOTICE OF PRIVACY PRACTICES
CALIFORNIA DEPARTMENT OF PUBLIC HEALTH
GENETIC DISEASE SCREENING PROGRAM,
THE CALIFORNIA PRENATAL SCREENING
PROGRAM EFFECTIVE DATE: July, 2015

THIS NOTICE DESCRIBES HOW MEDICAL AND OTHER PERSONAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED, AND HOW YOU GET ACCESS TO THIS INFORMATION. PLEASE REVIEW IT CAREFULLY.

Department's Legal Duties. The Genetic Disease screening program is required by law to maintain the privacy of protected health information. The Federal and State laws restrict the use, maintenance and, disclosure of personal information obtained by a State agency, and require certain notices to individuals whose information is maintained. The law also requires us to let you know promptly if a the privacy or security of your breach occurred that may have compromised information. 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

The Department of Public Health Program 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 personal information is not provided, problems could result such as not detecting an affected baby, 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 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 Prenatal Screening Program website: www.cdph.ca.gov/programs/pns. You may request a copy of the current policies or obtain more information about our privacy practices, by calling the numbers listed on the next page 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. 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, 1415 L Street, Suite 500, Sacramento, CA 95814, (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 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) 412-1502. 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

The California Newborn Screening Test

Newborn screening can prevent serious health problems or even save your baby's life. Newborn screening can identify babies with certain diseases so that treatment can be started right away. Early identification and treatment can prevent intellectual disability and/or life-threatening illness.

What Types of Diseases are Screened for in California?

To protect the health of all newborns, California state law requires that all babies must have the Newborn Screening (NBS) Test before leaving the hospital. The test screens for specific diseases in the following groups:

Metabolic diseases - affect the body's ability to use certain parts of food; for growth, energy and repair.

Endocrine diseases - babies make too much or too little of certain hormones that affect body functions.

Hemoglobin diseases - affect the type and amount of hemoglobin in red blood cells, often leading to anemia and other problems.

Other genetic diseases - Cystic Fibrosis, Severe Combined Immunodeficiency (SCID), Adrenoleukodystrophy (ALD).

How is the Test Done and Who Pays for it?

A few drops of blood taken from the baby's heel are put on special filter paper. Medi-Cal, health plans, and most private insurance will pay for the test. The cost is included in the hospital bill.

Make Sure You Get This Booklet!

Make sure you get the booklet "Important Information for Parents About the Newborn Screening Test" from your prenatal care provider or go to our website at www.cdph.ca.gov/nbs.

