



THE CALIFORNIA
EXPANDED AFP
SCREENING
PROGRAM

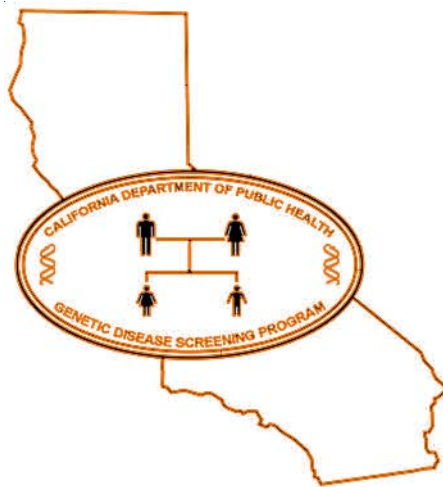
PROGRAM BOOKLET FOR
PREGNANT WOMEN OF
All Ages

Quad Marker Screening
at 15-20 weeks

California Department of Public Health - Genetic Disease Screening Program

The California Expanded AFP 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 participation, write to the 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*
www.dhs.ca.gov/gdb

January 2008

The California Expanded AFP Screening Program

Program Booklet for Pregnant Women of All Ages

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THE CALIFORNIA
EXPANDED AFP
SCREENING PROGRAM

**Program Booklet For Pregnant
Women of All Ages**

**Quad Marker Screening
at 15-20 weeks**

The California Expanded AFP 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 fetus (unborn baby). For some women this means testing the fetus for birth defects. The Expanded AFP blood test and the NTD/SCD blood test are screening tests that can help detect some birth defects.

The screening tests help detect certain birth defects: Open neural tube defects, Abdominal wall defects, Down syndrome, Trisomy 18, and Smith-Lemli-Opitz syndrome (these birth defects are described on pages 6 and 7).

It is a woman's own decision whether to have a blood screening test. A consent/refusal form is at the end of this booklet.

The California program offers two types of blood tests for screening:

- ❖ **Expanded AFP Screening test** for women who have not had first trimester screening tests, (described on page 3).
- ❖ **NTD/SCD Screening test** designed for women who have had first trimester screening, CVS or PGD (described on page 9).

A screening test estimates the **chance (risk)** that the fetus has a certain birth defect. If the risk is high, a woman may then choose to have diagnostic testing. The blood tests for screening are called the **Expanded AFP Screening test** and the **NTD/SCD Screening test** (SCD described on page 7).

Blood Test for Expanded AFP Screening

What does the blood test for screening involve?

This blood test for screening is also called a Quad Marker test because four markers are used to screen for birth defects. A small amount of blood is taken from the pregnant woman's arm. Her blood is tested for the amount of:

- ❖ **AFP** (alpha-fetoprotein)
- ❖ **hCG** (human chorionic gonadotropin)
- ❖ **uE3** (unconjugated estriol)
- ❖ **INH** (dimeric inhibin-A, DIA)

These are made by the mother's placenta and the unborn baby (fetus). At each week of pregnancy, there are different amounts of these substances in the mother's blood.



When is the blood test for screening done?

The blood test for screening can only be done **between 15 and 20 weeks of pregnancy**. Ultrasound is the best way to know when a pregnant woman is between 15 and 20 weeks.

The results of the blood test are sent to the patient's doctor or clinic within 1-2 weeks.

Each pregnancy is different, so screening test results from previous pregnancies do not apply to this pregnancy.

Test Results and Follow-Up

What does a “screen negative” result mean with a blood test?

It means that the chance for *certain* birth defects is low enough that the Program does not consider follow-up tests necessary. Since the blood test is just a screening test, there is still a chance that the fetus may have a problem - even when the test result is "screen negative".

What does a “screen positive” result mean?

It means that the chance for *certain* birth defects in this pregnancy is higher than usual. It is a clue for health care providers to look for possible birth defects.

To determine the reason for the “screen positive” result, **genetic counseling and follow-up diagnostic tests are offered.** They are paid for by the Program at a State-approved Prenatal Diagnosis Center.

NOTE: *Most women with "screen positive" results will have normal follow-up tests and healthy babies.*

SUMMARY OF BLOOD TEST RESULTS

"screen negative" ⇒ No follow-up tests are offered by the Program.

"screen positive" ⇒ Follow-up tests are provided at no extra cost at a State-approved Prenatal Diagnosis Center.

Test Results and Follow-Up

If the 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**. When authorized, these are the follow-up services paid for by the Program:

- ❖ **Genetic counseling** - A genetic counselor reviews the pregnancy and family medical history. The risks and benefits of further testing are explained.
- ❖ **Ultrasound** - A picture of the fetus is made using sound waves. The ultrasound shows the age of the fetus and whether there are twins. This special ultrasound at a Prenatal Diagnosis Center can also detect certain birth defects.
- ❖ **Amniocentesis** - A small amount of fluid is taken out of the uterus by experienced State-approved doctors. The fluid and the fetal cells in it are tested for specific birth defects.

Genetic counseling can help a woman decide whether to accept or refuse further testing (such as ultrasound or amniocentesis.)



What if the follow-up tests show that the fetus 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 possible outcomes and options. The Program does not pay for any other medical services after the authorized follow-up tests. Referrals for special support services are available.

Screening Tests Help Detect These Birth Defects

What birth defects may be found through follow-up testing?

Open neural tube defects, Abdominal wall defects, Down syndrome, Trisomy 18, Smith-Lemli-Opitz syndrome, and some other birth defects may be found.

Neural Tube Defects (NTDs)

As a fetus 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.

If there is an opening in the spine, it is called **spina bifida**. This defect often causes paralysis of the legs. It may also cause loss of bowel and bladder control. Frequently, there is water-on-the-brain (hydrocephaly) which requires surgery.

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



Abdominal Wall Defects

Abdominal Wall Defects (AWD) are problems involving the baby's abdomen and intestines. Intestines and other organs are formed outside the body. Surgery after birth may be performed to correct the defect.

Screening Tests Help Detect These Birth Defects

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 mental retardation and other 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 fetuses with Trisomy 18 are lost through miscarriage. Babies born with Trisomy 18 have severe mental retardation and physical defects. They usually do not live past early infancy.

Smith-Lemli-Opitz Syndrome (SLOS), SCD

This is a very rare birth defect. Babies with Smith-Lemli-Opitz syndrome (SLOS) cannot make cholesterol normally. Babies need to make cholesterol, even before birth, to help their brains and bodies develop. Babies born with this condition are mentally retarded and may have many physical defects.

Screen positive results for **S**LOS can also indicate increased chances for **C**ongenital abnormalities and fetal **D**emise (fetal death). That is why this screening is also called **SCD** screening.

How Many Birth Defects Are Found?

The Expanded AFP Program screens for certain birth defects. The program is able to detect most, but not all, of these birth defects.

Among all women who have screening and follow-up tests, the Program detects about:

- 97% of anencephaly
- 80% of open spina bifida
- 85% of abdominal wall defects
- 80% of Down syndrome
- 67% of Trisomy 18
- 60% of Smith-Lemli-Opitz syndrome (SLOS)

Even when the blood test is “screen negative,” there is still a chance the fetus may have a problem.

Can the Expanded AFP Screening Program detect every type of birth defect?

No. There are birth defects which **cannot** be detected by Expanded AFP Screening.

Blood Test for NTD/SCD Screening

The blood test for NTD/SCD Screening can be done at 15-20 weeks of pregnancy, instead of the Expanded AFP Screening blood test. NTD/SCD screening is only done when a woman has already had a First Trimester screening result, CVS, or Preimplantation Genetic Diagnosis.

- ❖ First Trimester Screening is a special ultrasound and blood test combination. It is usually done between 9 and 13 weeks of pregnancy. It is an early screening test for Down syndrome and Trisomy 18.
- ❖ Chorionic Villus Sampling (CVS) is a test done on cells from the placenta between 10 and 14 weeks of pregnancy. It is a diagnostic test for chromosomal abnormalities in the fetus such as Down syndrome and Trisomy 18.
- ❖ Preimplantation Genetic Diagnosis (PGD) is a test done on embryos before implantation during In Vitro Fertilization. When PGD is done to detect chromosome abnormalities, it can diagnose Down syndrome and Trisomy 18.

For women who have had any of these three tests, the blood test for NTD/SCD Screening can be requested **instead of** Expanded AFP Screening.

Test results for NTD/SCD do not include results for the chromosome abnormalities Down syndrome and Trisomy 18. The test results show what the chances are that the woman is carrying a fetus with an Open Neural Tube Defect and SLOS (SCD Screening).

If the result is “Screen Negative,” follow-up tests through the Program are not considered necessary. If the result is “Screen Positive,” the Program will pay for Genetic Counseling and follow-up tests at a State-approved Prenatal Diagnosis Center (see pages 4-5).

Women who have had First Trimester Screening or PGD should discuss with their doctor the choice between the NTD/SCD Screening test or the full Expanded AFP Screening test.

Diagnostic Tests Instead of Screening Tests for Birth Defects

Women should speak with their doctor or other health care professional about the difference between a diagnostic test and a blood test for screening. A **diagnostic test** can tell whether or not the fetus **actually has** a certain birth defect. Diagnostic tests during pregnancy can include **amniocentesis** or **chorionic villus sampling (CVS)** (see page 11). Some women may have medical reasons to consider diagnostic testing instead of screening.

Who should consider diagnostic testing instead of screening?

- ❖ women age 35 and older at delivery
- ❖ 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 insulin-dependent diabetes
- ❖ women with high risk pregnancies

Who can help you make a decision between diagnostic and screening tests?

Before deciding between a screening test and a diagnostic test, a woman should talk to her doctor and/or a genetic counselor. A genetic counselor can explain your choices in detail and answer any questions. Your doctor can refer you to a genetic counselor at a State-approved Prenatal Diagnosis Center. Ask your doctor for the pamphlet "Prenatal Diagnosis".

Diagnostic Tests Instead of Screening Tests for Birth Defects

The two diagnostic tests that women may choose instead of screening are **amniocentesis** or **chorionic villus sampling (CVS)**.

Amniocentesis is usually done between **15 and 20 weeks** of pregnancy. A doctor withdraws a small amount of amniotic fluid from the uterus. Amniocentesis is over 99% accurate in diagnosing Down syndrome and other chromosomal defects. Measuring AFP in amniotic fluid can help detect open neural tube defects.

Miscarriage due to the procedure occurs in less than 1 in 300 of amniocentesis tests. Complications are rare. There is a small risk of infection or leaking fluid.

The cost of amniocentesis is about \$2000 to \$3000. The patient or her insurance is responsible for payment. The Expanded AFP Program does not pay for amniocentesis unless authorized after a positive screening test.

Chorionic Villus Sampling (CVS) is usually done between **10 and 14 weeks**. This test involves obtaining cells from the developing placenta instead of the amniotic fluid. Cells from the placenta are examined for chromosomal defects such as Down syndrome, Trisomy 18 and others.

CVS is 98% accurate for the diagnosis of Down syndrome and other chromosomal defects. After CVS, an NTD/SCD blood test is recommended to screen for other defects (see page 9). Miscarriage rates due to CVS may be the same as after amniocentesis when CVS is performed by experienced doctors.

The cost for CVS is about \$2100 to \$3500. The patient or her insurance is responsible for payment. The Expanded AFP Program does not pay for CVS.

Summary of Prenatal Testing Described in this Booklet

SCREENING TESTS		
TEST	WHEN DONE	DESCRIPTION
Expanded AFP Screening Test	15-20 weeks of pregnancy	<ul style="list-style-type: none"> * A woman's blood specimen is tested for various substances present during pregnancy. * It <u>estimates</u> chances of having a fetus with certain birth defects. * If the result is "screen positive", the Program pays for follow-up services at a State-approved Prenatal Diagnosis Center.
NTD/SCD Screening Test	15-20 weeks of pregnancy	<ul style="list-style-type: none"> * A woman's blood specimen is tested after First Trimester screening, CVS, PGD. * It <u>estimates</u> chances of having a fetus with Neural Tube Defects or SLOS. * If the result is "screen positive", the Program pays for follow-up services at a State-approved Prenatal Diagnosis Center.

Summary of Prenatal Testing Described in this Booklet

DIAGNOSTIC TESTS		
TEST	WHEN DONE	DESCRIPTION
CVS (outside the Program)	10-14 weeks of pregnancy	<ul style="list-style-type: none"> * Examines fetal cells taken from the placenta (in the uterus). * <u>Diagnoses</u> 98% of Down syndrome and other chromosomal defects. * Not a test for neural tube defects and SLOS. An NTD/SCD screening test is recommended at 15-20 weeks.
Amniocentesis	15-20 weeks of pregnancy	<ul style="list-style-type: none"> * Examines fetal cells taken from the amniotic fluid that surrounds the fetus. * <u>Diagnoses</u> 99% of Down syndrome and other chromosomal defects. * Measuring AFP in amniotic fluid can help identify neural tube defects. * May be offered by the Program after a blood test with a screen positive result. * May be offered outside the Program for women who choose diagnosis instead of screening.

Program Fee

What is the fee for Expanded AFP or NTD/SCD Screenings?

Presently, the fee is **\$162**. Check with the doctor or clinic about the most current fee. The fee covers the blood test *and* authorized follow-up services at a State-approved Prenatal Diagnosis Center. The program fee is the same for Expanded AFP screening and for NTD/SCD screening.

The Program mails a bill and insurance form to women who have the blood test. Women with private insurance should complete the insurance form and return it. **In most cases, health insurance companies and HMOs are required to cover the costs of the**

Expanded AFP testing after you pay any deductible or co-pay. There is an exception made for self-insured employers. Contact your health insurance provider to determine your plan's payment or co-pay for prenatal testing.



Women with Medi-Cal usually do not receive a bill. If they do, they should return the bill with their Medi-Cal number. Women without health insurance are responsible for the whole amount but may make monthly payments.

Any charges for drawing blood are not included in the program fee.

If you have questions about the blood test for screening or the cost, ask your doctor. After you have decided, please sign the consent/refusal form on the next page.

CLINICIAN'S COPY
(Must be filed in patient's chart.)

Patient's name _____
(PLEASE PRINT)

ID# _____

**CONSENT/REFUSAL FOR THE
CALIFORNIA EXPANDED AFP SCREENING PROGRAM**

1. I have read the information in this booklet about the **Blood Tests for Screening** (or have had it read to me).
2. I have been informed that:
 - a) the purpose of the blood tests is to screen for open neural tube defects, abdominal wall defects, Down syndrome, Trisomy 18, and Smith-Lemli-Opitz syndrome. However, not all such defects can be detected by the Program.
 - b) the NTD/SCD screening can be requested after First Trimester Screening, CVS or Preimplantation Genetic Diagnosis. It screens for open neural tube defects, abdominal wall defects, and Smith-Lemli-Opitz syndrome.
 - c) the NTD/SCD screening test does not include screening results for Down syndrome or Trisomy 18.
 - d) there are other birth defects that cannot be detected by either of these screening tests.
 - e) there is a fee for the screening which is the same for the Expanded AFP Screening or NTD/SCD Screening.
 - f) if the result is "screen positive," I will need to make a decision regarding follow-up testing. Authorized follow-up tests are covered by the Program at no additional charge. They will be discussed with me in more detail if offered.
 - g) if the result is "screen negative", the Program will not pay for any follow-up testing.
 - h) if the fetus is found to have a birth defect, the decision to continue or terminate the pregnancy will be entirely mine.
 - i) participation in the California Expanded AFP Screening Program is voluntary. I can refuse any test at any time.

(over)

TEAR HERE AND FILE IN PATIENT'S CHART

3. I have read the detection rates for certain birth defects as they are described in this booklet.
4. I have been informed that a blood specimen for the California Expanded AFP or NTD/SCD Screening is only reliable between 15 and 20 weeks of pregnancy.
5. I agree to pay any part of the Program fee that my insurance (or other entity) does not pay.
6. I understand that any blood specimens and information obtained during testing become the property of the California Department of Public Health. Confidentiality of the records is maintained. I consent that my specimens and information may be used for program evaluation or research by the Department, or Department-approved scientific researchers. I may revoke my consent for such use at any time by writing to the Prenatal Screening Branch, Genetic Disease Screening Program, 850 Marina Bay Parkway, F175, Richmond, CA 94804.
7. I have had my questions answered to my satisfaction.

TEAR HERE AND FILE IN PATIENT'S CHART

Yes	<p>I request that blood be drawn for the (check one):</p> <p><input type="checkbox"/> EXPANDED AFP SCREENING</p> <p style="text-align: center;">or</p> <p><input type="checkbox"/> NTD/SCD SCREENING</p> <p>Signed _____ Date _____</p> <p>My blood must be drawn between:</p> <p style="text-align: center;"> _____ and _____ month day year month day year </p>
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No	<p>I request that blood <u>not</u> be drawn for Expanded AFP Screening or NTD/SCD Screening.</p> <p>Signed _____ Date _____</p>
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PATIENT'S COPY

Patient's name _____
(PLEASE PRINT)

ID# _____

CONSENT/REFUSAL FOR THE CALIFORNIA EXPANDED AFP SCREENING PROGRAM

1. I have read the information in this booklet about the **Blood Tests for Screening** (or have had it read to me).
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 - a) the purpose of the blood tests is to screen for open neural tube defects, abdominal wall defects, Down syndrome, Trisomy 18, and Smith-Lemli-Opitz syndrome. However, not all such defects can be detected by the Program.
 - b) the NTD/SCD screening test can be requested after First Trimester Screening, CVS or Preimplantation Genetic Diagnosis. It screens for open neural tube defects, abdominal wall defects, and Smith-Lemli-Opitz syndrome.
 - c) the NTD/SCD screening test does not include screening results for Down syndrome or Trisomy 18.
 - d) there are other birth defects that cannot be detected by either of these screening tests.
 - e) there is a fee for the screening which is the same for the Expanded AFP Screening or NTD/SCD Screening.
 - f) if the result is "screen positive," I will need to make a decision regarding follow-up testing. Authorized follow-up tests are covered by the Program at no additional charge. They will be discussed with me in more detail if offered.
 - g) if the result is "screen negative", the Program will not pay for any follow-up testing.
 - h) if the fetus is found to have a birth defect, the decision to continue or terminate the pregnancy will be entirely mine.
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7. I have had my questions answered to my satisfaction.

Yes	<p>I request that blood be drawn for the (check one):</p> <p><input type="checkbox"/> EXPANDED AFP SCREENING</p> <p style="text-align: center;">or</p> <p><input type="checkbox"/> NTD/SCD SCREENING</p> <p>Signed _____ Date _____</p> <p>My blood must be drawn between:</p> <p style="text-align: center;">_____ and _____</p> <p style="text-align: center;">month day year month day year</p>
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No	<p>I request that blood <u>not</u> be drawn for Expanded AFP Screening or NTD/SCD Screening.</p> <p>Signed _____ Date _____</p>
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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 required 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:

<http://www.nationalcordbloodprogram.org/>; 866-767-6227

❖ National Marrow Donor Program:

<http://www.marrow.org/>; 800-627-7692

**NOTICE OF INFORMATION PRACTICES AND PRIVACY PRACTICES CALIFORNIA DEPARTMENT OF
PUBLIC HEALTH**

**GENETIC DISEASE SCREENING PROGRAM, EXPANDED AFP SCREENING PROGRAM
EFFECTIVE DATE JANUARY 2008**

**THIS NOTICE DESCRIBES HOW PERSONAL (INCLUDING MEDICAL) INFORMATION ABOUT YOU
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 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.

Continued

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

- For research studies, such as research related to preventing disease, 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 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 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 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 contacting the person listed below or consulting our website at www.dhs.ca.gov/gdb. 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 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 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. We may not be able to agree to your request.

Complaints. If you believe that we have not protected your privacy or have violated any of your 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 94234-7320, (916) 440-7432 or (877) 421-9634 TTY/TDD.

Continued

You may file a complaint by calling or writing the **Privacy Officer**, CA Department of Public Health, at the address and telephone number on the previous page. 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 of Civil Rights at 866-OCR-PRIV (866-627-7748) or 866-788-4989 TTY.

The Department cannot take away your health care benefits nor 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 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

THE CALIFORNIA NEWBORN SCREENING TEST

Newborn screening can save your baby's life or prevent serious brain damage. Newborn screening can identify babies with certain diseases so that treatment can be started right away. Early identification and treatment can prevent mental retardation and/or life-threatening illness.

What Types of Diseases are Screened for in California?

To protect the health of all its newborns, California state law requires that your baby 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

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.dhs.ca.gov/nbs.

