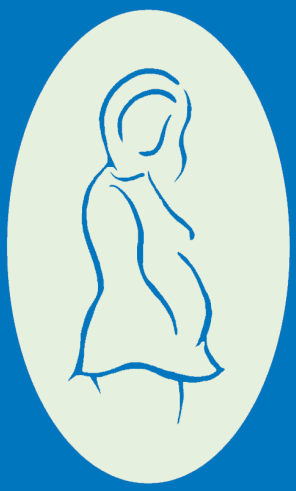
The California Prenatal Screening Program



Quad Marker Screening

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

Serum Integrated Screening

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

Full Integrated Screening

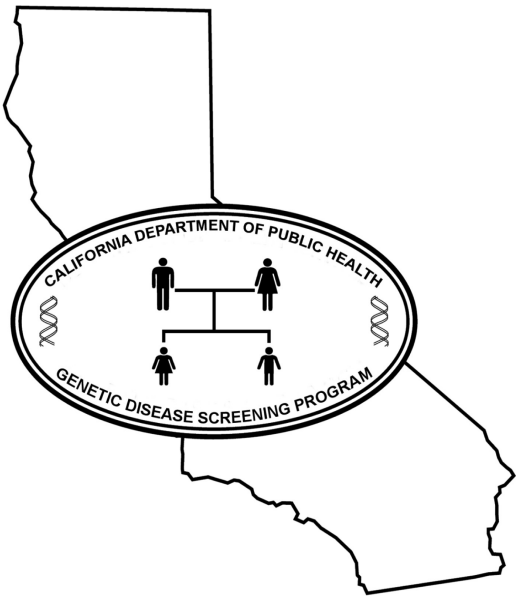
Combines Nuchal Translucency with first and second trimester blood test results.

Prenatal Patient Booklet - English

California Department of Public Health - Genetic Disease Screening Program
Prenatal Screening Program

The California Prenatal Screening Program is voluntary. Women can refuse testing without losing insurance benefit, 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 see our website www.cdph.ca.gov and click on the Prenatal Screening Section on the left.

March, 2009

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 fetus (unborn 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 mental retardation

Trisomy 18…….....mental retardation and physical birth defects

Trisomy 13..... severe physical birth defects and mental retardation

Neural Tube Defects.....such as spina bifida (open spine)

Abdominal wall defects….....the baby's intestines are formed outside the body

Smith-Lemli-Opitz syndrome …..SLOS is a very rare problem causing mental retardation and physical birth defects

see pages 15-16 for a description of these birth defects

A screening test estimates the chance (risk) that the fetus has a certain birth defect. This is called a "Risk Assessment". If the risk is high, a woman may then choose to have diagnostic tests.

It is a woman's own decision whether to have prenatal screening tests. A Consent or Decline form is on pages 20-21.

The California Prenatal Screening Program Offers Three Types of Screening Tests

- **Quad Marker Screening**
  One blood specimen drawn at 15 weeks – 20 weeks of pregnancy (second trimester)

Yellow Section, pages 5-6

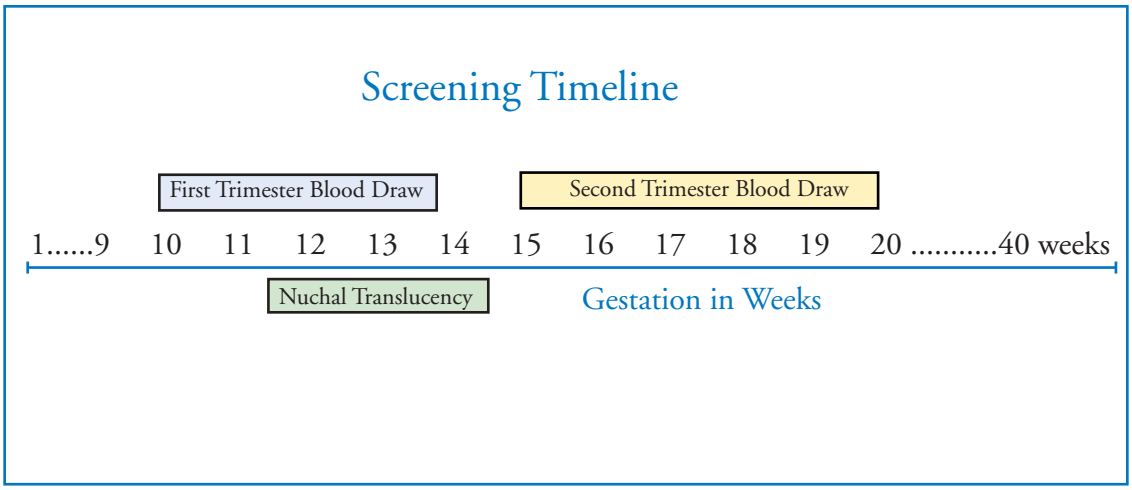
- **Serum Integrated Screening**
  Combines first trimester blood test results with second trimester blood test results

Blue Section, pages 7-8

- **Full Integrated Screening**
  Combines Nuchal Translucency results with first and second trimester blood test results

Green Section, pages 9-12

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



Blood Tests are Part of Prenatal Screening

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

PAPP-A ….. Pregnancy Associated Plasma Protein A
hCG…… Human Chorionic Gonadotropin
AFP …… Alpha-fetoprotein
uE3 ……. Unconjugated Estriol
Inhibin..... Dimeric Inhibin-A (DIA)

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

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.

Quad Marker Screening
at 15 to 20 weeks of pregnancy

Have your blood drawn between 15weeks 0days and 20weeks 0days.

You can have Quad Marker screening if you have NOT had blood screening tests for birth defects earlier in your pregnancy.

This Quad Marker screening tests four substances: AFP, hCG, uE3, and Inhibin. This screening gives you Risk Assessments for:

- Down syndrome (a type of mental retardation)
- Trisomy 18 (mental retardation and physical birth defects)
- Neural tube defects (such as spina bifida or anencephaly)
- SLOS (physical birth defects and mental retardation)

See pages 15-16 for a description of these birth defects

If you have CVS before Quad Marker Screening:

Chorionic villus sampling (CVS) is a prenatal diagnostic test for detecting birth defects at an early stage of pregnancy (see page 14). You will get a Risk Assessment only for Neural tube defects and SLOS. Diagnostic tests for Down syndrome and Trisomy 18 are conducted with CVS.

Tests Results (Risk Assessment)

A **Quad Marker** screening result is sent to your doctor about 7 - 10 days after blood draw. ***Your results are specific to you. They are either Screen Negative or Screen Positive.***

Screen Negative - This means that the risk (chance) of the fetus having any of these birth defects is low....low enough that the Program does not offer follow-up tests.

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

See page 14 for a description of these free follow-up services

Important!

A ***Screen Negative*** result **does not guarantee** that there are **no** birth defects.

A ***Screen Positive*** result does not always mean that there is a birth defect. Most women will have normal follow-up tests and healthy babies.

Birth Defects Found

Quad Marker Screening, together with follow-up diagnostic tests (if done), detects about:

- 80 out of 100 cases of Down syndrome
- 67 out of 100 cases of Trisomy 18
- 97 out of 100 cases of anencephaly
- 80 out of 100 cases of open spina bifida
- 85 out of 100 cases of abdominal wall defects
- 60 out of 100 cases of Smith-Lemli-Optiz syndrome (SLOS)

Prenatal Screening tests **cannot** detect 100 % of these birth defects.

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

Serum Integrated Screening:
Combining two Blood Tests

Serum is part of a blood specimen.

There are 2 Steps for Serum Integrated Screening:

1. Between 10weeks 0days and 13weeks 6days of pregnancy - have your first blood specimen drawn. The specimen is sent to the Program.
   Two substances are tested: PAPP-A and hCG.

2. Between 15 and 20 weeks of pregnancy - have your second blood specimen drawn. The specimen is sent to the Program. Four substances are tested: AFP, hCG, uE3, Inhibin.

Test Results (Risk Assessments)

A ***Serum Integrated Screening*** result is based on combining the two blood test results. There are no results for the first blood test alone. The combined results are sent to your doctor about 7 – 10 days after the second blood draw.

This Serum Integrated result gives you Risk Assessments for:

- Down syndrome (a type of mental retardation)
- Trisomy 18 (mental retardation and physical birth defects)
- Neural Tube Defects (such as spina bifida or anencephaly)
- SLOS (physical birth defects and mental retardation)

See pages 15-16 for a description of these birth defects

Your results are specific to you. They are either Screen Negative or Screen Positive.

Screen Negative - This means that the risk (chance) of the fetus having any of these birth defects is low….low enough that the Program does not offer follow-up tests.

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

See page 14 for a description of these free follow-up services

Important!

A ***Screen Negative*** result **does not guarantee** that there are **no** birth defects.

A ***Screen Positive*** result does not always mean that there is a birth defect. Most women will have normal follow-up diagnostic tests and healthy babies.

Birth Defects Found

SERUM INTEGRATED SCREENING (two blood tests at different times), together with follow-up diagnostic tests, if done, detects about:

- 85 out of 100 cases of Down syndrome
- 79 out of 100 cases of Trisomy 18
- 97 out of 100 cases of anencephaly
- 80 out of 100 cases of open spina bifida
- 85 out of 100 cases of abdominal wall defects
- 60 out of 100 cases of SLOS

Prenatal Screening tests **cannot** detect 100 % of these birth defects.

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

Full Integrated Screening:
Two Blood Tests Plus Nuchal Translucency

WHAT IS NUCHAL TRANSLUCENCY (NT)? This is a type of ultrasound done only by doctors with special training. It measures the back of the fetus' neck. This measurement helps screen for Down syndrome and Trisomy 18.

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

A **Full Integrated Screening** result is based on combining the two blood test results and the nuchal translucency (NT) ultrasound.

There are 3 Steps for Full Integrated Screening:

1. Between 10weeks and 13weeks 6days of pregnancy - have your first blood specimen drawn. The blood specimen is sent to the Program. Two substances are tested: PAPP-A and hCG.

2. Between 11weeks 2days and 14weeks 2days of pregnancy - have your nuchal translucency ultrasound done. The results are sent to the Program.

3. Between 15 and 20 weeks of pregnancy - have your second blood specimen drawn. The blood specimen is sent to the Program. Four substances are tested: AFP, hCG, uE3, and Inhibin.

Step 1 and step 2 together are called First Trimester Screening.
When Step 3 is completed, this is called Full Integrated Screening.

Results are sent to your doctor as each blood specimen is received by the Prenatal Screening Program.

Test Results (Risk Assessment)

First Trimester Screening is the first blood test + Nuchal Translucency (NT). In the first trimester, there is only screening for Down syndrome and Trisomy 18.

First trimester results can either be **Preliminary Risk Assessment** or **Screen Positive**.

First Trimester Results

Preliminary Risk Assessment	Screen Positive
This Preliminary result for Down syndrome and Trisomy 18 indicates a *risk low* enough that the Program does not offer follow up services.	This means that there is an early *high risk* for either Down syndrome or Trisomy 18.
The result is sent to your doctor after the Program receives the 1st Trimester blood specimen + NT results.	The result is sent to your doctor after the Program receives the 1st Trimester blood specimen + NT results.
IMPORTANT: To complete screening, you must have your second blood test drawn at 15-20 weeks of pregnancy!	There are two choices after a *Screen Positive* result: -- Go to a State-approved Prenatal Diagnosis Center for follow up tests OR -- Have a second blood test at 15-20 weeks for Full Integrated Screening.

Full Integrated Screening (continued)

Second Trimester Results

Full Integrated Screening is when the second blood test results are put together with the first trimester results. This Full Integrated Screening will give a refined and improved Risk Assessment for:

- Down syndrome (a type of mental retardation)
- Trisomy 18 (mental retardation and physical birth defects)

Full Integrated Screening will also give a Risk Assessment for:

- Neural Tube Defects (such as spina bifida or anencephaly)
- SLOS (physical birth defects and mental retardation)

See pages 15-16 for a description of these birth defects

Your results are specific to you. They are either Screen Negative or Screen Positive.

Screen Negative - This means that the risk (chance) of the fetus having any of these birth defects is low…. low enough that the Program does not offer follow-up tests.

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

See page14 for a description of these free follow-up services

Important!

A ***Screen Negative*** result **does not guarantee** that there are **no** birth defects

A ***Screen Positive*** result does not always mean that there is a birth defect. Most women will have normal follow-up diagnostic tests and healthy babies.

Birth Defects Found

FULL INTEGRATED SCREENING (two blood tests + NT), together with follow-up diagnostic tests, if done, detects about:

- 90 out of 100 cases of Down syndrome
- 81 out of 100 cases of Trisomy 18
- 97 out of 100 cases of anencephaly
- 80 out of 100 cases of open spina bifida
- 85 out of 100 cases of abdominal wall defects
- 60 out of 100 cases of Smith-Lemli-Optiz syndrome (SLOS)

Prenatal Screening tests **cannot** detect 100 % of these birth defects.

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

Comparing The Three Types of Prenatal Screening Tests

	Quad Marker Screening	Serum (blood) Integrated Screening	Full Integrated Screening
When is screening done?	One blood Specimen drawn 15 to 20 weeks of pregnancy.	First blood specimen drawn 10weeks to 13weeks 6days of pregnancy. Second blood specimen drawn 15 to 20 weeks of pregnancy.	First blood specimen drawn 10weeks to 13weeks 6days of pregnancy. Nuchal Translucency Ultrasound at 11weeks 2days to 14weeks 2days Second blood Specimen drawn 15 to 20 weeks of pregnancy.
What are the Detection Rates? (When diagnostic tests are done after *Screen Positive*)	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	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	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

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

Test Results and Follow Up

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**.

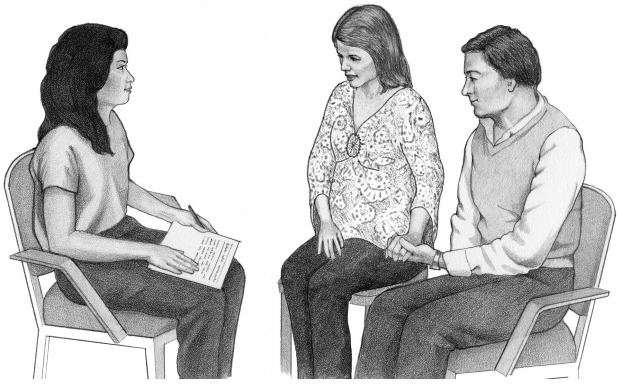
- First, all women get **genetic counseling**. A genetic counselor reviews the test results and family medical history. The counselor explains the diagnostic tests which may be offered.

Tests Which May be Offered:

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

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

- **Amniocentesis**: This may be offered after 15 weeks of pregnancy. A small amount of fluid is taken out of the uterus by experienced State-approved doctors. Tests are done for specific birth defects.



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

What if the diagnostic 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 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 are available.

Birth Defects Found Through Diagnostic Testing

Down syndrome, Trisomy 18, Trisomy 13, Neural tube defects, Abdominal wall defects, Smith-Lemli-Opitz syndrome, and some other 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 mental retardation and physical defects.

Trisomy 13

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

Neural Tube Defects (NTD)

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.

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 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 is usually performed to correct the defect.

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 born with this condition are mentally retarded 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.

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 fetus 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

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

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 $162. Check with the doctor or clinic about the most current fee. **The fee covers the blood tests and authorized follow-up services at a State-approved Prenatal Diagnosis Center**.

The Program charges $162 when:

- there is one blood test or two
- there is one fetus or two.

The Program fee *does not* cover:

- blood draw charges
- nuchal translucency

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 Prenatal Screening is completed, the Prenatal Program saves some blood specimens and gives them to 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 fetus 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 Full Integrated Screening.

Yes I Consent to Screening	I consent to participate in the California Prenatal Screening Program. I request that blood be drawn for Prenatal Screening. I agree that my specimen may be used for research by the Department of Public Health, or Department approved researchers, unless I mark the box below. ☐ I decline the use of my specimen for research. The Department will maintain confidentiality according to applicable laws and regulations. Signed_____Date_____

No I Decline Screening	I decline to participate in the California Prenatal Screening Program. I request that blood not be drawn for Prenatal Screening. Signed_____ Date_____

PATIENT COPY

Consent or Decline
California Prenatal Screening Program

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2. I understand that:

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No I Decline Screening	I decline to participate in the California Prenatal Screening Program. I request that blood not be drawn for Prenatal Screening. Signed_____ Date_____

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:
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,
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. 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.

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

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.cdph.ca.gov/nbs.