Newborn Screening Tests in Washington and Oregon

What is Newborn Screening?
State laws require that all babies born in Washington and Oregon be tested for congenital disorders. Babies born at home must be tested (by your midwife in WA, in OR by any provider) within 48 hours of birth. To obtain the blood sample, the baby's heel is pricked. Several large drops of blood are collected on a filter paper card, dried, and sent for testing to the state Newborn Screening Laboratory. There must be enough blood to completely soak through the filter paper in the test circles, or the lab may refuse to test the sample.

As a parent, may I refuse to have the test done?
You may refuse the test if your religious beliefs and practices do not allow it. If you refuse to have the test done, you must sign the back of the WA Newborn Screening Card (or the OR refusal form) which states that you declined to have your baby tested for the inherited problems. You have the right to ask your midwife to discuss the screening process and to provide the screening result to you.

Why is my baby tested, and what does it cost?
The NBS program detects inherited problems in newborn babies. If left untreated, these problems can lead to slow growth, blindness, brain damage and possibly death. A newborn baby may look perfectly healthy, but still have an inherited disease. Finding these problems early and treating them promptly prevents many serious complications. The test costs **$135.10 in WA**, and **$175 in OR** (pre-paid), and all or part of this fee may be reimbursed to you by insurance - please keep a copy of your check for you to submit directly to claims.

Why should my baby have a second screen?
The first test finds most of the babies with conditions on our panel, but it takes a while for some conditions to show up. That is why a second screen at about 7 to 14 days is very important for your baby.

What tests are performed on my baby's blood, and how common are these disorders?
Please see the attached table for more details.

How can I find out about the results of my baby's newborn screen?
Your provider should receive the report of the tests, usually 7-14 days after the sample is collected. If there is an abnormal result, notification will occur sooner.

My baby has a negative test. What does that mean?
A negative test means that your baby probably does not have one of the inherited disorders tested for by newborn screening. No test is 100 % accurate. There is a slight chance that a test will show a negative result when there is a problem. Parents should always report symptoms to their doctor.

My doctor asked for another sample because the first one was unsatisfactory. What does that mean?
All samples are examined in the testing laboratory for acceptability. If a sample is unsuitable for testing, another should be collected.

My baby has a positive test. What does that mean?
If one of your baby's tests is positive, the doctor may repeat the Newborn Screening test or request another type of blood test. If an inherited problem is found, your baby's doctor will discuss the next steps with you; this may include genetic counseling. Most metabolic disorders are treatable, but treatment must begin quickly to prevent damage.

Test results show my baby is a carrier of the gene for an inherited disease. What does that mean?
A carrier is someone who does not have the disease itself, but can pass it to their children. These babies tend to be as healthy as babies who are not carriers. The parents should discuss the meaning of being a carrier with their doctor or genetic counselor.

Privacy and security of screening specimen / information forms
The specimen/information form submitted to the department pursuant to (WAC 246-650-020) becomes the property of the state of Washington upon receipt by the Washington state public health laboratory. (FAQ Note: This does mean that the state does not require your permission or any notification to use or share the sample for any other testing or research purpose as they see fit, pursuant only to HIPAA regulations regarding medical records privacy.)

What happens to my child's newborn screening specimen after testing is complete?
The specimen / information form shall be retained until the child is twenty-one years old in accordance with the requirements for hospitals specified in (RCW 70.41.190). After this time the form will be destroyed. Exception for parental request: Upon request of a parent or guardian (or adult patient), the department will destroy the specimen / information form only after all required screening tests have been performed and if the patient's screening/clinical status related to these tests is not in question.
For more information, please see http://doh.wa.gov/NBS, or http://public.health.oregon.gov/LaboratoryServices/NewbornScreening/Pages/index.aspx, and genes-r-us.uthscsa.edu

<u>By selecting and initialing the Informed Choice Checklist for this document, you are agreeing to the following</u>:

I have read and understand the above information, and had the opportunity to ask questions and do my own research. I understand that detecting metabolic disorders is time-critical, that the tests are not 100% accurate, and that the tests do not negate the importance of attentive parents identifying a sick newborn in time to prevent damage. My choice for having my midwife perform this test on my newborn is (please also mark your choice here, for your own recollection/records):

_____ **I DO NOT** want my newborn screened, and agree to sign a refusal form for my midwife.
_____ **I DO** want my newborn screened, and have provided a check for the state fee; $135.10 WA, $175 OR.
_____ **I DO** want my newborn screened, but I live in Oregon and chose to have this done by my doctor.

	Newborn Screening includes at least these tests in Washington (Oregon screening is similar)		
	Disorder	**Incidence**	**Details**
Amino Acid Disorders	Argininosuccinic acidemia (ASA), and Citrullinemia (CIT)	1 : 128,000	ASA and CIT-I are two similar disorders that affect the way the body processes protein.
	Homocystinuria (HCY)	1 : 200,000	Homocystinuria affects the way the body processes protein.
	Maple syrup urine disease (MSUD)	1 : 200,000	Maple syrup urine disease (MSUD) affects the way the body processes protein.
	Phenylketonuria (PKU)	1 : 15,000	Phenylketonuria (PKU) affects the way the body processes protein.
	Tyrosinemia type I (TYR-I)	1: 100,000	TYR-I affects the way the body processes protein.
Fatty Acid Disorders	Carnitine uptake deficiency (CUD)	1 : 175,000	CUD affects the way the body transports fats.
	Long-chain L-3-hydroxy acyl-CoA (LCHAD) deficiency, and Trifunctional protein (TFP) deficiency	1 : 105,000	LCHAD/TFP deficiencies affect the way the body breaks down fats.
	Medium-chain acyl-CoA dehydrogenase (MCAD) deficiency	1 : 20,000	MCAD deficiency affects the way the body breaks down fats.
	Very-long chain acyl-CoA dehydrogenase (VLCAD) deficiency	1 : 121,000	VLCAD deficiency affects the way the body breaks down fats.
Organic Acid Disorders	3-hydroxy-3-methylglutaric aciduria (HMG)	unknown	HMG affects the way the body processes protein and fats.
	Beta-ketothiolase deficiency (BKT)	unknown, very rare	BKT deficiency affects the way the body processes protein and fats.
	Glutaric acidemia type I (GA-I)	1 : 137,000	GA-I affects the way the body processes protein.
	Isovaleric acidemia (IVA)	1 : 96,000	IVA affects the way the body processes protein.
	Methylmalonic acidemias (CblA,B and MUT), and Propionic acidemia (PROP)	1 : 57,000	MMA/PA are disorders that affect the way the body processes protein.
	Multiple carboxylase deficiency (MCD)	unknown, very rare	MCD affects the way the body uses biotin (a vitamin) to help break down proteins and process fats and carbohydrates.
Other Disorders	Biotinidase deficiency (BIOT)	1 : 60,000	Biotinidase deficiency affects the way the body recycles biotin, one of the B complexvitamins.
	Congenital adrenal hyperplasia (CAH)	1 : 16,000	Congenital adrenal hyperplasia (CAH) occurs when the adrenal glands do not function properly.
	Congenital hypothyroidism (CH)	1 : 3,500	Congenital hypothyroidism (CH) occurs when the thyroid gland fails to develop or function properly.
	Cystic fibrosis (CF)	1 : 3,500	Cystic fibrosis (CF) affects the body's control of salt levels, causing thick, sticky mucus to build up in the lungs and digestive system and other organs.
	Galactosemia (GALT)	1 : 50,000	Galactosemia affects the way the body processes the sugar galactose, a component of milk and dairy products.
	Hemoglobinopathies (Hb)	1 : 5,000	Hemoglobinapthy is a term used to describe disorders caused by the presence of abnormal hemoglobin production in the blood, such as thalassemia or sickle cell.
	Note: new tests are routinely added to the above as they become available to the state labs.		

Newborn screening test refusal form - State of Oregon

By selecting to decline this test, and initialing that selection on the Informed Choices Checklist, you agree to the following:

I have read the Department of Human Services brochure entitled Newborn Screening could save your Infant's Life. This brochure explains newborn screening for cystic fibrosis, metabolic, endocrine and hemoglobin disorders.

I have been told and I understand that state law requires newborn screening for all infants born in Oregon because of the benefit to the infant and family of early detection and treatment of disorders on the screening panel.

I have been told and I understand that NBS detects more than 30 disorders whose symptoms may not appear for several weeks or months. I have been told and I understand that the risk of my infant having one of these conditions is approximately 1:1000.

I have been told and I understand that untreated, these conditions may cause permanent damage to my child. If affected and not treated, my infant may suffer serious mental retardation, growth failure and in some cases death.

I have discussed the testing with my provider. He/She has explained and I understand all the risks involved if my child is not screened. I have been informed and I understand the nature of the screening and how the screening sample is collected.

I object to newborn screening and I do not want screened for these conditions. I have freely made my decision without force or encouragement from my doctor, hospital personnel or state officials.