Information about services or follow-up:
If your baby does have one of these disorders, the program will make sure your baby's doctor knows where your baby can get specialty medical treatment if needed. You may be contacted by Children's Developmental Services (CDS) to offer to check your baby for developmental delays or learning problems. Also, some of the information gathered at your baby's doctor's office will be shared with us to help us make sure that your baby is getting the best care possible. The Newborn Bloodspot Screening laws can be viewed online at www.mainepublichealth.gov\bloodspot.

To order additional copies of this publication or if you have questions about the content, please call:
Maine CDC Newborn Bloodspot Screening Program
207-287-5357 (V) or 1-800-698-3624 (V)
TTY users call Maine relay 711.

DHHS
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Last update: November 2017

Newborn Bloodspot Screening Tests: They Could Save Your Baby's Life

Maine Newborn Bloodspot Screening Program

Why does my baby need newborn screening tests?

By law, all newborns are tested for several rare but serious medical conditions. Babies with these conditions may look healthy at birth. If not treated, these conditions can cause problems such as intellectual and developmental disability, serious illness, and even death. With treatment, these problems may be prevented.

How will my baby be tested?

A nurse or other medical professional will take a few drops of blood from your baby's heel. This blood sample is sent to a newborn screening laboratory.

When should the blood sample be taken?

The blood should be drawn when your baby is between 24 and 48 hours old.

How will I get the test results?

Your baby's doctor will contact you if the results suggest that your baby may have one of these conditions. The doctor will talk with you about the results and what needs to be done next.

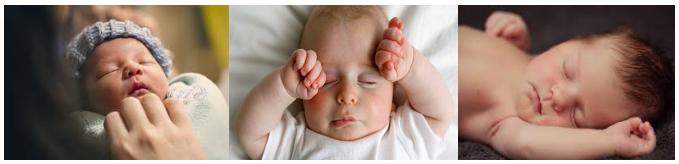
Ask about the test results when you see your baby's doctor.

What if my baby needs to be retested?

Sometimes, a baby needs to be tested again. This does not necessarily mean that your baby has a medical condition. Retesting may need to be done if:

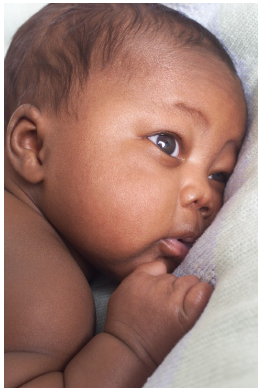
- The blood sample was taken before your baby was 24 hours old
- There was a problem with the way the blood sample was taken
- The first test showed a possible medical condition

Your baby's doctor or the Maine Newborn Bloodspot Screening Program will contact you about any positive results, possible health problems or if your baby needs more testing. It is important to get this testing done right away.



What tests are done?

The tests that are done depend on the state you live in. Each state screens for a slightly different list of conditions. In general, your baby will be screened for laboratory markers for conditions that fall into one of the following groups:



- Metabolic conditions, which affect how the body processes food
- Endocrine conditions, which affect the levels of important hormones
- Hemoglobin conditions, which affect the blood and cause anemia, infections, and other health problems
- A pulmonary condition, which affects growth and the lungs
- Immune conditions, which affect how the body fights infections.

See insert for a list of the conditions screened for in Maine. Newborn screening may find babies with conditions not on this list. Screening may also find a baby that carries only one gene for a condition. Most babies with one gene will not get sick from the condition.

Screening for more conditions may be available at other laboratories for a fee.

How are these conditions treated?

The treatment for each condition is different. Treatment may include a special diet, hormones, and/or medications.

If your baby has one of these conditions, it is very important to start the treatment as soon as possible.

What if I have more questions?

Ask your baby's doctor or contact the Maine Newborn Bloodspot Screening Program. See our contact information on the back of this brochure.

This material was developed by the New England Regional Genetics Group, Public Health Education Collaborative with funding provided by HRSA, U.S. Department of Health and Human Services

The Maine Newborn Bloodspot Screening provides information on some rare disorders of body chemistry. These screening tests may not pick up all newborns with these rare disorders. Even if the results of these screening tests are normal, there may be other medical problems that cannot be detected by these tests. It is important for your baby to have regular check-ups and good medical care. This blood test is only a screen.

List of Core Conditions:

Each baby born in Maine is screened for laboratory markers of the conditions listed below. This list is correct as of ***April 1, 2021*** but may change as conditions are added or removed from the testing panel.

3-Hydroxy-3-Methyglutaric Aciduria (HMG)
3-Methylcrotonyl-CoA Carboxylase Deficiency (3MCC)
Argininosuccinic Aciduria (ASA)
B-Ketothiolase Deficiency (BKT)
Biotinidase Deficiency (BIOT)
Carnitine uptake Defect/Carnitine Transport Defect (CUD)
Citrullinemia Type I (CIT)
Classic Galactosemia (GALT)
Classic Phenylketonuria (PKU)
Congenital Adrenal Hyperplasia (CAH)
Congenital Hypothyroidism (CH)
Cystic Fibrosis (CF)
Glutaric Acidemia Type I (GAI)
Holocarboxylase Synthase Deficiency (MCD)
Homocystinuria (HCY)
Isovaleric Acidemia (IVA)
Long-chain L-3 Hydroxyacyl-CoA Dehydrogenase Deficiency (LCHAD)
Maple Syrup Urine Disease (MSUD)
Medium-chain Acyl-CoA Dehydrogenase Deficiency (MCAD)
Methylmalonic Acidemia (MUT)
Methylmalonic Acidemia Cobalamin A, B (Cbl A, B)
Mucopolysaccharidosis Type I (MPS-1)
Pompe Disease
Propionic Acidemia (PROP)
S,C Disease (Hb S/C)
S/βeta-Thalassemia (Hb S/βTh)
Severe Combined Immunodeficiencies (SCID)
Spinal Muscular Atrophy (SMA):
S,S Disease (Sickle Cell Anemia) (Hb SS)
Trifunctional Protein Deficiency (TFP)
Tyrosinemia Type I (TYR I)
Very Long-chain Acyl-CoA Dehydrogenase Deficiency (VLCAD)
X-Linked Adrenoleukodystrophy (X-ALD)

vList of Secondary Conditions:

Screening for Core disorders may show information about the following disorders:

2-Methylbutyrylglycinuria (2MBG)
2-Methyl-3-Hydroxybutyric Aciduria (2M3HBA)
3-Methylglutaconic Aciduria (3MGA)
Argininemia (ARG)
Benign Hyperphenylalaninemia (H-PHE)
Biopterin Defect in Cofactor Biosynthesis (BIOPT (BS))
Biopterin Defect in Cofactor Regeneration (BIOPT (REG))
Carnitine Acylcarnitine Translocase Deficiency (CACT)
Carnitine Palmitoyltransferase Type II Deficiency (CPT II)
Carnitine Palmitoyltransferase Type I Deficiency (CPT 1A)
Citrullinemia, Type II (CIT II)
Galactokinase Deficiency (GALK)
Galactoepimerase Deficiency (GALE)
Glutaric Acidemia Type II (GA2)
Hypermethioninemia (MET)
Isobutyrylglycinuria (IBG)
Medium-chain Ketoacyl-CoA Thiolase Deficiency (MCAT)
Methylmalonic acidemia with homocystinuria (Cbl C,D)
T-cell Related Lymphocyte Deficiencies
Tyrosinemia, Type II (TYR II)
Tyrosinemia, Type III (TYR III)
Various other hemoglobinopathies (Var Hb)

Information about sample storage and use:

After the blood sample has been tested, it is kept within our program until further notice to make sure it can be used to benefit your child in the future. The samples that show a positive result are sometimes used to help our program make sure that we find these rare, serious disorders in all infants tested. The samples are kept in a secure freezer, and only removed for further testing at the request of the parent, your baby's doctor and our program. Specimens can be destroyed at the parent's request.

For more information about newborn bloodspot screening, religious objections, blood sample use call **Maine Newborn Bloodspot Screening Program Telephone: 207-287-5357 (V) or 1-800-698-3624 (V)**
TTY Users: Dial 711 (Maine Relay)