For questions contact:

Iowa Newborn Screening Program (INSP)

1-866-890-5965

or

Iowa Department of Public Health

1-800-383-3826

321 East 12th Street
Des Moines, IA 50319-0075
www.idph.state.ia.us/genetics

For additional copies contact:

State Hygienic Laboratory

(515) 725-1630

University of Iowa Children's Hospital
University of Iowa Health Care

Center for Congenital and Inherited Disorders

State Hygienic Laboratory — Iowa's Environmental and Public Health Laboratory — Est. 1904 — The University of Iowa

IDPH Iowa Department of Public Health

Iowa Newborn Screening Program

Phone: 1-(866)-890-5965
Fax: 1- (319)-384-5116

The Iowa Newborn Screening Program

Checking your baby head to heel.

How Will My Baby Be Tested?

A few drops of blood are taken from your baby's heel and put on special paper.

The state public health laboratory does the testing.

Why Does My Baby Need Newborn Screening?

Newborn screening is a way to find babies who may have some serious medical conditions. These conditions are often treatable, but may not be visible at birth.

Without early treatment, these conditions can lead to serious illness, disability or death.

The state law in Iowa is that all babies get this testing done.

Talk to your health care provider if you have questions.

How Will I Find Out The Test Results?

The Newborn Screening Program will notify your baby's health care provider. Please ask about your baby's newborn screening results at your first well child check.

If there is an abnormal result, you will get a call telling you what to do next.

What Do I Need To Do if My Baby Needs Repeat Testing?

Don't panic! If you get a call from your baby's health care provider, it does not always mean your baby has one of these serious medical conditions.

Take your baby to get the repeat testing done as soon as you have been asked to do so!

What Happens to My Baby's Blood After Testing is Done?

Left-over blood specimens are available for other testing for the baby if needed and are used to make sure quality testing is done, and to develop and improve newborn screening tests.

If a parent or legal guardian provides consent, the left-over blood specimen may be used for research to improve the health of mothers and children, and to investigate other conditions such as cancer, chronic disease or environment-related illnesses.

Questions? Call the Iowa Department of Public Health at 1-800-383-3826.

What will my baby be screened for?

AMINO ACIDEMIAS

- Argininosuccinic aciduria (ASA)*
- Citrullinemia, type 1 (CIT)*
- Homocystinuria (HCY)*
- Maple syrup urine disease (MSUD)*
- Classic phenylketonuria (PKU)*
- Tyrosinemia, type I (TYR-1) *

ORGANIC ACIDEMIAS

- Glutaric acidemia type I (GA-1)*
- 3-Hydroxy 3-methylglutaric aciduria (HMG)*
- Isovaleric acidemia (IVA)*
- 3-Methylcrotonyl-CoA carboxylase (3-MCC)*
- Methylmalonic acidemia - cobalamin disorders (Cbl-A,B) & methylmalonyl-CoA mutase deficiency (MUT) *
- βeta-Ketothiolase (βKT)*
- Propionic acidemia (PROP)*
- Holocarboxylase synthetase deficiency (MCD) *

ENDOCRINE

- Congenital adrenal hyperplasia (CAH)*
- Primary congenital hypothyroidism (CH)*

* Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) Recommended Uniform Screening Panel - Core Panel

More information continued on next side...

What will my baby be screened for? (cont.)

FATTY ACID OXIDATION DISORDERS

- Carnitine uptake defect & Carnitine transport defect (CUD) *
- Long-chain L-3 hydroxyacyl-CoA dehydrogenase (LCHAD)*
- Medium chain acyl-CoA dehydrogenase deficiency (MCAD) *
- Trifunctional protein deficiency (TFP)*
- Very long-chain acyl-CoA dehydrogenase deficiency (VLCAD) *

HEMOGLOBINOPATHIES

- Sickle cell anemia (Hb SS)*
- Hemoglobin SC disease (Hb SC)*
- Sickle beta-thalassemia (Hb Sβ)*

OTHER

- Biotinidase deficiency (BIOT)*
- Cystic fibrosis (CF)*
- Classic galactosemia (GALT)*
- Severe combined immunodeficiencies (SCID)*

* Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) Recommended Uniform Screening Panel - Core Panel

For more disorder specific information go to:

http://www.idph.state.ia.us/genetics/neonatal_parent_page.asp