

PROGRAM SHARING INFORMATION THROUGH CHARM

Birth and Death Certificates

The Office of Vital Records and Statistics administers the statewide system of Vital Records and Statistics by documenting and certifying the facts of births, deaths and family formation for the legal purposes of the citizens of Utah, participates in the National Vital Statistics Systems and responds to the needs of health programs, health care providers, businesses, researchers, educational institutions and the Utah public for data and statistical information.

<http://health.utah.gov/vitalrecords/AboutUs.htm>

Newborn Hearing Screening - Its Time Has Come

What's Happening?

After several years of study and consideration, the Utah Legislature determined that testing the hearing of newborns would be very helpful to Utah families. In 1998 they passed legislation that newborns in hospitals with over 100 births per year would have a hearing screening prior to discharge. In 1999 all births (including home births) were required to have a hearing screen.

Why Screen?

A hearing loss cannot be seen. Infants with hearing loss cry and make other sounds just like babies with normal hearing.

Hearing loss is the most common birth defect In Utah, about 1 in every 300 babies is born with a permanent hearing loss. You need normal hearing to develop normal speech and language.

How Is It Done?

There are two types of tests which are used in screening infants. Neither one of them hurt.

- Otoacoustic Emissions (OAE) - Soft sounds are directed into the ear through a tiny ear probe. A computer then measures the inner ear responses.
- Automated Auditory Brainstem Response (AABR)

Small probes are placed in the infant's ears. Soft clicking sounds are directed into the ear. A computer measures the response to sounds through wires attached to the infant's head.

A simple hearing test at birth can prevent big problems later on!

Early identification is the "best chance to learn." If your baby missed or did not pass the newborn hearing screening it is very important to have a follow-up hearing screening. Please contact the birth hospital to make arrangements or contact Hearing, Speech and Vision Services, Utah Department of Health at (801) 584-8215.

<http://health.utah.gov/cshcn/HSVS/nbhear.html>

NEWBORN SCREENING (heelstick) tests the following at birth:

METABOLIC DISORDERS

- **Biotinidase deficiency:** a recessive disorder of biotin metabolism
- **Galactosemia:** a recessively inherited genetic disorder in which the individual is completely or partially incapable of normal metabolism of galactose due to a deficiency of the galactose-1-phosphate uridyltransferase enzyme
- **Fatty Acid Oxidation Disorders:** a recessive disorder resulting from an enzyme deficiency needed for the break down of fatty acids
 - Carnitine uptake/transport defects
 - Multiple acyl-CoA dehydrogenase deficiency (MADD)
 - Short chain acyl-CoA dehydrogenase deficiency (SCAD)
 - Medium chain acyl-CoA dehydrogenase deficiency (MCAD)
 - Long chain 3 hydroxyacyl-CoA dehydrogenase deficiency (LCHAD)
 - Very long chain acyl-CoA dehydrogenase deficiency (VLCAD)
 - Carnitine-Acylcarnitine Translocase Deficiency
 - Carnitine Palmitoyl Transferase-1 Deficiency
- **Amino acid disorders:** a recessive disorder resulting from an enzyme deficiency needed for amino acid metabolism or transport
 - Arginase Deficiency
 - Argininosuccinate lyase deficiency (ASA)
 - Citrullinemia
 - Homocystinuria
 - Hyperphenylalanemia, including phenylketonuria
 - Tyrosinemia
- **Organic Acid Disorders:** a recessive disorder resulting from an enzyme deficiency in the intermediary metabolism of amino acids or fatty acids
 - Beta-ketothiolase deficiency
 - Glutaric acidemia, Type 1
 - Isobutyry
 - CoA dehydrogenase deficiency
 - Isovaleric acidemia
 - Malonic aciduria
 - Maple syrup urine disease
 - Methylmalonic acidemias
 - Propionic acidemia
 - 3-Hydroxy-3-methylglutaryl (HMG) CoA lyase deficiency
 - 2-Methyl-3-hydroxybutyryl CoA dehydrogenase deficiency
 - 2-Methylbutyryl CoA dehydrogenase deficiency
 - Multiple carboxylase deficiency

ENDOCRINE DISORDERS:

- **Congenital adrenal hyperplasia (CAH):** a genetic disorder in which there are defects in the enzymes of the adrenal cortex required for the biosynthesis of adrenal corticosteroids
- **Congenital hypothyroidism:** a disorder in which the newborn is unable to secrete or produce thyroxine normally

HEMOGLOBIN DISORDERS:

- **Sickle cell disease and other hemoglobinopathies:** a recessively inherited genetic defect of the structure of hemoglobin found in red blood cells

These are disorders which may have significant mortality and morbidity when not diagnosed presymptomatically and may not be consistently identified clinically in the neonatal period. Early detection and treatment may improve the health and development of newborns identified with these disorders.

<http://health.utah.gov/newbornscreening/>

Welcome to USIIS!

The Utah Statewide Immunization Information System (USIIS) is a statewide information immunization system that contains immunization histories for Utah residents of all ages.

Only authorized health care users have access to USIIS. For more information or to schedule a USIIS demonstration, please contact the Utah Immunization Program at 801-538-9450.

<http://www.usiis.org/index.shtml>

ONLINE BROCHURE

As parents, we want our children to grow up healthy.

One of the best gifts we can give them is to make sure they get immunizations (shots)—to protect them from childhood diseases like measles and pertussis (whooping cough).

It can be hard to keep track of your child's immunizations, especially if you switch doctors or use a different clinic.

Now, USIIS can help!

It's an immunization registry. USIIS is a confidential, computerized information system that keeps complete, up-to-date records of your child's immunization history. USIIS will maintain your child's immunization records even if you change health-care providers.

USIIS helps you and health-care providers know what immunizations your child has had and what he or she still needs.

Many Utah health-care providers take part in USIIS.

Ask your doctor's office, public health clinic or community health center if it takes part.

Or look for a posted USIIS certificate. This booklet gives only basic facts about USIIS. Be sure to talk with your doctor, nurse, or health-care provider about all of your child's health needs.

USIIS instantly tells doctors and nurses the information in your child's immunization records.

It helps ensure that your child:

- gets immunizations on time
- won't get an unneeded vaccine (due to lost or missing records).

It makes it easier for you to get your child's immunization records for child care, school or camp.

It makes it easier for health-care providers to:

- print out up-to-date immunization records

- send your child's immunization reminder to you.

How will my child's immunization records be included in USIIS?

The records will be entered:

- from birth records filed with the Utah Department of Health
- when your child gets immunizations at a participating clinic
- when you enroll in a participating health plan or public health program. The immunization records will be shared with authorized health-care providers, health plans, schools, child care centers, and public health programs, unless you choose to withdraw your child from USIIS.

If you wish to withdraw your child from USIIS, or if you have questions, call the USIIS HelpLine at 801-538-6872, the Immunization Hotline at 800-275-0659, or visit the USIIS Web site at www.usiis.org.

Are records kept confidential?

Yes! Only authorized members* of these groups have access to USIIS:

- **health-care providers and public health programs**—to see what immunizations your child needs and to update his or her records
 - **schools and child care centers**—to make sure every child's immunizations are current to avoid disease outbreaks (without having to trouble parents and health-care providers for records)
 - **health plans** (your insurance company)—to aid in quality assurance and public health measurements.
- *To be authorized, members must sign an agreement and follow strict confidentiality and security policies. All data transferred electronically is safeguarded

Consent to Withdraw from the Utah Statewide Immunization Information System

http://www.usiis.org/acrobat_files/brochure1.pdf

The Utah Birth Defect Network (UBDN)

seeks to prevent birth defects and secondary disabilities by monitoring occurrence, conducting research, providing education and outreach. We hope that the information on this Web site will meet your needs. If you need further information about birth defects or a referral to available services please contact us at 801-257-0566 or 1-866-818-7096.

How Does the UBDN Monitor Birth Defects?

Why does the Utah Birth Defect Network (UBDN) monitor birth defects in Utah?

81.5% of birth defect cases in Utah from 1999-2003 have no known cause

*1 in 4 infant deaths in Utah is attributable to birth defects

*1 in 50 births in Utah is affected by a birth defect tracked by the UBDN

Tracking and studying birth defects in Utah provides the information needed to monitor the burden of disease locally and statewide, to assess services, to allocate resources for optimal care, and to evaluate prevention efforts.

Which birth defects does the UBDN track?

- All major birth defects
- Some minor defects are excluded

The UBDN tracks all major structural birth defects. However, some of the more mild conditions are not tracked due to limited resources. These mild conditions include those such as heart findings detected in the preterm baby and that often resolve over time (e.g., patent ductus arteriosus); mild conditions not leading to treatment (e.g., coronal hypospadias not needing surgery); or conditions that usually do not lead to major medical concerns except perhaps in later stages of life (mitral prolapse).

How does the UBDN monitor birth defects?

- Reports from hospitals, labs, clinics and birthing facilities
- Medical records abstraction
- Data analysis

Utah administrative rule R398-5 gives the UBDN legal authority to collect information about children born in Utah with birth defects. Under this rule, all hospitals and birthing centers located in Utah are required to report a specific set of information to the UBDN any time a baby is born with a birth defect. Once the UBDN receives a report of a birth defect, a UBDN staff member goes out to the reporting facility and collects information from the medical records of the infant and the mother. The collected information is then entered into a secure database. Analysis is then performed by an epidemiologist to identify rates, trends, risk factors, and causes. The UBDN takes great care to insure the confidentiality and security of all information that is collected. All identifying information is removed from the data before analysis.

<http://health.utah.gov/birthdefect/leftNav/monitoring.html>