



# PUBLIC HEALTH BULLETIN

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In this issue: South Dakota newborn screening data, 2000-2008	page 3
South Dakota newborn hearing data, 2005-2008	page 16
Selected morbidity report, January - May 2009	page 18

## Lung Cancer in South Dakota, 2006

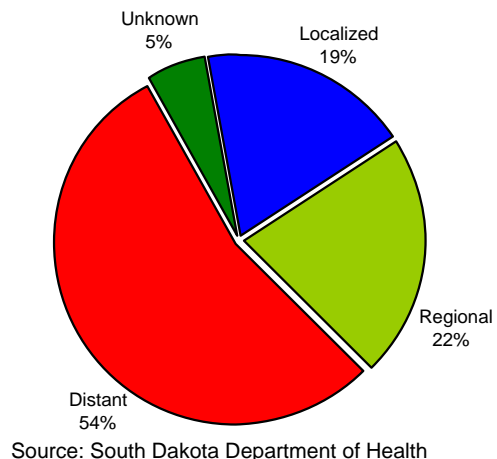
By the South Dakota Cancer Registry, South Dakota Department of Health

The South Dakota Cancer Registry has released the 2006 lung cancer data. For 2002-2006, the average number of new lung cancer cases per year was 519 and the average number of annual deaths due to lung cancer was 426.

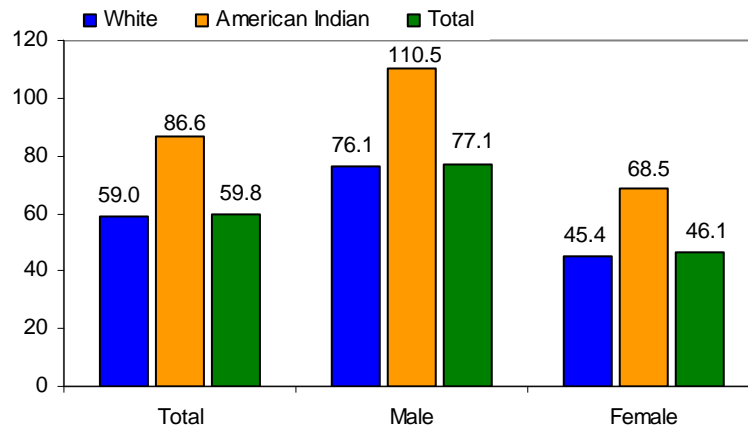
Incidence 2006		Mortality 2006	
Number of cases		Number of deaths	
Total	524	Total	435
Males	300	Males	248
Females	224	Females	187
White	490	White	407
American Indian	30	American Indian	26
Median age at diagnosis	72 yrs	Median age at death	73 yrs
Mode	69 yrs	Mode	78 yrs
Age range at diagnosis	30-97 yrs	Age range at death	30-101 yrs
SD age-adjusted incidence rate	62.9	SD age-adjusted death rate	52.6
US SEER age-adjusted incidence rate (2005) *61.1		US SEER age-adjusted death rate (2005) *52.8	

Rates per 100,000 U.S. 2000 standard population  
 \* 2006 US SEER age-adjusted rates not available  
 Source: South Dakota Department of Health

The circle graph at the right displays the SEER Summary Stage at diagnosis for 2006 lung cancer cases in South Dakota. As shown, over half of the cases were diagnosed at the more advanced stage of distant. Prognosis is best for lung cancers diagnosed at an earlier stage.

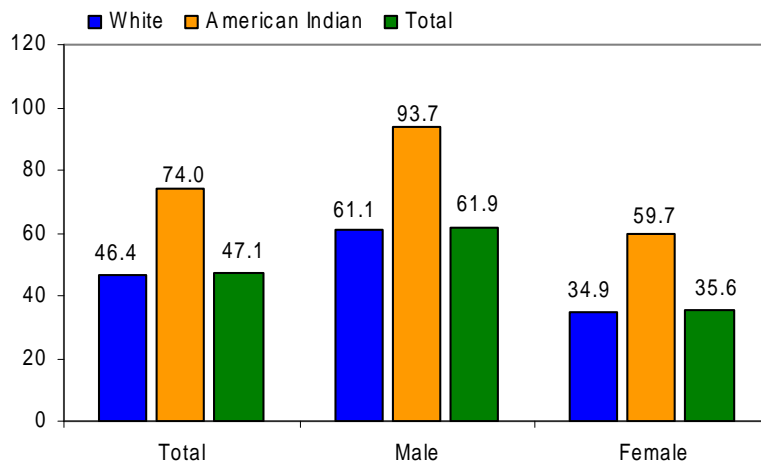


See below for the age-adjusted lung cancer incidence rate by race and gender in South Dakota for 2002-2006. Lung cancer is the most common cancer worldwide. Smoking is the number one cause of lung cancer.



Source: South Dakota Department of Health

Nationally, the risk of dying from lung cancer is more than 23 times higher among men who smoke and about 13 times higher among women who smoke compared with someone who has never smoked. Secondhand smoke causes approximately 3,000 lung cancer deaths among U.S. nonsmokers each year. See below for the age-adjusted lung cancer death rate by race and gender in South Dakota for 2002-2006.



Source: South Dakota Department of Health

The South Dakota QuitLine offers free assistance to help South Dakotans quit tobacco. The toll-free phone number is 1-866-737-8487. Coaches are available who help develop personalized plans to help quit smoking.

For additional information, please contact Kay Dosch, South Dakota Cancer Registry Coordinator, at 605-773-6345 or 800-738-2301 or see the website at <http://doh.sd.gov/SDCR/> for the entire lung cancer monograph.

## **South Dakota Newborn Screening Program Data Summary, 2000-2007**

*By Lucy Fossen, RN, Newborn Screening Coordinator*

*Office of Family Health, South Dakota Department of Health*

Newborn screening is a preventative public health surveillance program performed in every state in the United States and in many countries throughout the world. It is aimed at the early identification of infants affected by certain genetic/metabolic conditions. Early identification of the disorders is crucial. Timely intervention can lead to a significant reduction of the morbidity and mortality associated with these disorders. SDCL 34-24-17 requires all infants born in South Dakota be screened for metabolic disease as prescribed by the Department of Health.

The following program data for 2000 -2007 with provisional data for 2008 is presented by the South Dakota Department of Health Newborn Screening Program (SDNSP). The data source is the Electronic Vital Records System (EVRSS). To assure each infant born in South Dakota is screened for metabolic disease per SDCL 34-24-17, newborn screening metabolic records are matched to birth records.

Prior to January 1, 1997, newborn screening testing in South Dakota was performed by seven different laboratories across the state. The fragmented system raised concerns about the quality of testing and the overall newborn screening process. In February 1995, a team of outside professionals with expertise in newborn screening was invited to review and make recommendations for the program. The expert panel recommended a centralized laboratory system to improve the reliability, uniformity, and testing efficiency of newborn screening in the state.

Centralized newborn screening laboratory services began in 1997 with Sanford Laboratories (previously named Sioux Valley Clinical Laboratories). In June 2007, the Department of Health contracted with the University of Iowa Hygienic Laboratory (UHL) in Ankeny, Iowa for newborn screening laboratory services. The designated laboratory is responsible for the testing, quality control of laboratory testing, and the initial notification of newborn screening test results.

Since 1973, South Dakota has mandated infants to be screened for PKU (began 1973), Congenital Hypothyroidism (1982), Galactosemia (1991), Biotinidase Deficiency (2005), Congenital Adrenal Hyperplasia (2005), Hemoglobinopathies (2005), Amino Acid Disorders(2005), Fatty Acid Oxidation Disorders(2005), Organic Acidemia (2005), and Cystic Fibrosis (2007). Refer to Table A and B.

### **Newborn Screening Process**

**TESTING:** Newborn screening specimens are collected between 24-48 hrs of age. The specimens arrive at UHL by courier and are tested for multiple conditions.

**FOLLOW-UP:** The submitter is responsible for accurate and complete information on the specimen collection card in order to quickly locate babies with abnormal results. Using phone and fax, the UHL notifies the healthcare provider identified on the infant's specimen collection card of the screening findings and further testing recommendations. The UHL also notifies the SDNSP. The healthcare provider contacts the parents to bring the baby in for evaluation and testing. With the notification, healthcare providers are provided education to share with parents regarding signs/symptoms. The SDNSP continues follow-up until confirmatory tests are completed.

**DIAGNOSIS/INTERVENTION:** When repeat or confirmatory testing confirms screening results, the physician consults with and/or refers the infant to a pediatric subspecialist appropriate to the disorder. Confirmatory testing received by the SDNSP is forwarded to program medical consultants for review and further recommendations.

**TREATMENT & MANAGEMENT:** Once a medical determination is made, treatment begins. Treatment may occur prior to diagnosis for some life-threatening conditions upon the recommendation of the UHL Medical Director or the SDNSP Medical Consultant. Parents are also referred to the department's HealthKiCC program, which provides financial assistance for medical appointments, procedures, treatments, medications and travel reimbursement for children with certain chronic health conditions. Genetic counseling and dietary management is also part of treatment and management.

**NEWBORN SCREENING INFORMATION MATRIX**  
**Disorders Currently Screened in South Dakota – September 2008**

**Table A**

<b>Disorders (est. prevalence for SD)</b>	<b>Definition</b>	<b>Screening Test</b>	<b>Impact Without Early Treatment</b>	<b>Treatment</b>	<b>Benefits of Early Treatment</b>
<b>Biotinidase deficiency</b> (1 in 60,000)	Deficiency of biotin, part of the Vitamin B complex	Enzyme assay: Measure Biotinidase activity	Seizures, damage to immune system, mental retardation, hearing loss	Oral biotin supplementation	Prevent all adverse consequences
<b>Congenital adrenal hyperplasia (CAH)</b> (1 in 20,000)	Impaired production of cortisol and other adrenal hormones	Measure Adrenal hormone: 17 – hydroxyprogesterone (17-OHP) level	Salt loss & shock may result in early sudden death, virilization & abnormal growth	Cortisol & salt- retaining hormone replacement	Prevent death, reduce virilization & abnormal growth
<b>Congenital hypothyroidism</b> (1 in 3,000)	Inadequate production of thyroid hormone	Measure thyroid stimulating hormone (TSH) level	Mental retardation, growth failure	Thyroid hormone replacement	Normal growth and mental development
<b>Cystic fibrosis</b> (1 in 3,000 expected)	Defect in the cystic fibrosis transmembrane conductance regulator (CFTR) gene	Measure immunoreactive trypsinogen (IRT) level	Thick, sticky mucus builds up in the lungs and digestive system	Pancreatic enzymes, vitamin supplements, chest physiotherapy, antibiotics	Improve physical growth, cognitive function & possibly lung function
<b>Galactosemia</b> (1 in 47,000)	Inability to break down galactose, a major sugar found in milk	Enzyme assay: measure galactose-1-phosphate uridyl transferase (GALT) activity	Galactose accumulates in vital organs, leading to severe mental retardation, liver disease, blindness, overwhelming infections and death	Dietary restriction of galactose	Prevent death, improve mental function & reduce other morbidity
<b>Hemoglobinopathies (Sickle Cell Disease)</b> (1 in 10,000)	Production of abnormal hemoglobin	Separate and visualize hemoglobin proteins by electrophoresis	Severe infections and possible death	Antibiotic prophylaxis to help prevent infections & parental education to recognize health crises	Prevent death, reduce infections and other morbidity
<b>Amino acid disorders (AA) includes PKU</b> (1 in 10,000) see list Table B	Inability to break down amino acids, found in all foods containing protein	Measure amino acid levels by MS/MS	Mental retardation, seizures, coma & death	Dietary restriction of offending amino acid(s) using a special metabolic formula	Prevent mental retardation and other neurological damage
<b>Fatty acid disorders (FAO) includes MCAD</b> (1 in 13,000) see list Table B	Inability to process or break down fats in the body due to missing or dysfunctional enzymes	Measure acylcarnitine levels by MS/MS	Serious damage to brain, liver, heart, eyes and muscles & death	High carbohydrate, low-fat diet & avoidance of fasting	Prevent mental retardation and other neurological damage
<b>Organic acid disorders (OA)</b> (1 in 25,000) See list Table B	Inability to process or break down organic acids, byproducts of protein and fatty acid metabolism	Measure acylcarnitine levels by MS/MS	Severe nerve and physical damage & death	Dietary restriction of offending amino acid(s) and use of a special metabolic formula	Prevent mental retardation and other neurological damage

Note: Accurate incidence data is not available for some disorders. The prevalence rates listed here are anticipated.

**Table B**  
**South Dakota Newborn Screening Program List of Disorders, June 2007**

**AMINO ACIDEMIAS AND UREA CYCLE DISORDERS (AA)**

- (ASA) Argininosuccinate acidemia\*
- (CIT I) Citrullinemia or ASA Synthetase Deficiency\*
- (HCY) Homocystinuria (cystathionine beta synthetase)
- (MSUD) Maple Syrup Urine Disease\*
- (PKU) Phenylketonuria\*
- (TYR-1) Tyrosinemia Type 1\*
- (ARG) Arginiemia\*\*
- (BIOPT-BS) Defects of bipterin cofactor biosynthesis\*\*
- (CIT-II) Citrullinemia type II\*\*
- (BIOPT-RG) Defects of bipterin cofactor regeneration\*\*
- (H-PHE) Benign hyperphenylalaninemia\*\*
- (MET) Hypermethioninemia\*\*
- (TYR II) Tyrosinemia type II\*\*
- (TRY III) Tyrosinemia type III\*\*

**ORGANIC ACIDEMIAS (OA)**

- (GA-1) Glutaric acidemia type 1\*
- (HMG) 3-Hydroxy 3-methylglutaric aciduria \*
- (IVA) Isovaleric acidemia\*
- (3-MCC) 3-Methylcrotonyl-CoA carboxylase\*
- (Cbl-A,B) Methylmalonic acidemia (vitamin B12 disorders)\*
- (BKT) Beta Ketothiolase\*
- (MUT) Methylmalonic Acidemia (methylmalonyl-CoA mutase)\*
- (PROP) Propionic acidemia\*
- (MCD) Multiple carboxylase\*
- (2M3HBA) 2-Methyl-3-hydroxybutyric aciduria\*\*
- (2MGB) 2-Methylbutyryl-CoA dehydrogenase\*\*
- (3MGA) 3-Methylglutaconic aciduria\*\*
- (Cbl-C, D) Methylmalonic acidemia\*\*
- (IBG) Isobutyryl-CoA dehydrogenase\*\*
- (MAL) Malonic acidemia\*\*

**FATTY ACID OXIDATION DISORDERS (FAO)**

- (CUD) Carnitine uptake defect (Carnitine transport defect)
- (LCHAD) Long-chain L-3 hydroxyacyl-CoA dehydrogenase\*
- (MCAD) Medium chain acyl-CoA dehydrogenase\*
- (TRP) Trifunctional protein deficiency\*
- (VLCAD) Very long-chain acyl-CoA dehydrogenase\*
- (CACT) Carnitine acylcarnitine translocase\*\*
- (CPT-Ia) Carnitine palmitoyltransferase I\*\*
- (CPT-II) Carnitine palmitoyltransferase II\*\*
- (GA-II) Glutaric acidemia Type II\*\*
- (MCKAT) Medium-chain ketoacyl-CoA thiolase\*\*
- (M/SCHAD) Medium/Short chain L-3-hydroxy acyl-CoA dehydrogenase\*\*
- (SCAD) Short-chain acyl-CoA dehydrogenase\*\*

**OTHER**

- Biotinidase deficiency \*
- Congenital adrenal hyperplasia (CAH) \*
- Congenital hypothyroidism (CH) \*
- Cystic Fibrosis \*
- Galactosemia \*
- Sickle cell disease and other hemoglobin disorders \*

\* American College of Medical Geneticists Recommended Disorders - Core Panel

\*\* American College of Medical Geneticists Recommended Disorders - Secondary Targets

Caveat: The possibility of a false negative or a false positive result must always be considered when screening newborns for metabolic disorders.

**Newborn Screening Outcome Data, 2000-2008**

The data source for newborn screening outcomes is the South Dakota Department of Health’s Electronic Vital Records and Screening System (EVRSS). South Dakota metabolic records are matched with birth records to assure that every infant born in the state obtains a newborn screening per SDCL 24-24-17. Data was collected 04/24/2009, with 2008 data provisional.

**Table D. South Dakota Newborn Screening Outcome Data, 2000-2008**  
(2008 data provisional)

Year	Births	Never Tested	PKU	CH	GAL	BT	CAH	HB	Ex. Screen	CF
2000	10,589	36; deceased = 32	0	4	1	N/A	N/A	N/A	N/A	N/A
2001	10,786	41; deceased = 36	2	6	0	N/A	N/A	N/A	N/A	N/A
2002	11,015	41; deceased = 38	1	3	0	N/A	N/A	N/A	N/A	N/A
2003	11,504	40; deceased = 32	0	4	0	N/A	N/A	N/A	N/A	N/A
2004	11,805	60; deceased = 57	1	6	1	N/A	N/A	N/A	N/A	N/A
2005	11,960	54; deceased = 42	0	3	1	0	0	0	3	N/A
2006	12,387	51; deceased = 39	1	5	0	0	0	2	4	N/A
2007	12,815	63; deceased = 51	0	9	1	0	0	2	0	1
2008*	12,632	62; deceased = 52	1	6	0	2	0	1	3	3

Note: Data does not include some variant forms of metabolic disorders, hemoglobinopathy traits, or carriers of cystic fibrosis.

**2008 Detections by race**

Despite the fact that newborn screening (PKU) has been underway for more than 40 years in the United States, data only allows estimates of the incidence and prevalence. One reason is that

states vary in their definitions of hyperphenylalaninemia and PKU. There are large variations in the incidence of PKU by subpopulations. Individuals of Northern European ancestry and American Indian/Alaska Native individuals have a higher incidence than black, Hispanic, and Asian individuals. Accurate incidence data for some subpopulations is unavailable.

**Table E. South Dakota Newborn Screening Detections by Race, 2000-2008**  
(2008 data provisional)

Infant's Race	2008 Births	2008 Infants Detected									
		PKU	CH	CAH	HB	GAL	BT	AA	FAO	OA	CF
White	10,028	1	5	0	1	0	2	1	1	0	3
African American	184	0	0	0	0	0	0	0	0	0	0
American Indian	1,947	0	1	0	0	0	0	0	1	0	0
Asian/Pacific Islander	147	0	0	0	0	0	0	0	0	0	0
More than 1 race listed	311	0	0	0	0	0	0	0	0	0	0
Unknown/other	15	0	0	0	0	0	0	0	0	0	0
<b>Total</b>	<b>12,632</b>	<b>1</b>	<b>6</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>2</b>	<b>1</b>	<b>2</b>	<b>0</b>	<b>3</b>

### Newborn Screening - Cystic Fibrosis

Cystic Fibrosis (CF) is an autosomal recessive disease requiring a mutation on each of the two copies of chromosome 7 inherited from our parents. CF can cause damage to a number of different body organs, including the lungs, and upper respiratory tract, gastrointestinal tract, pancreas, liver, sweat glands, and genitourinary tract. Cystic Fibrosis screening was mandated June 1, 2007 after two years of being an optional test.

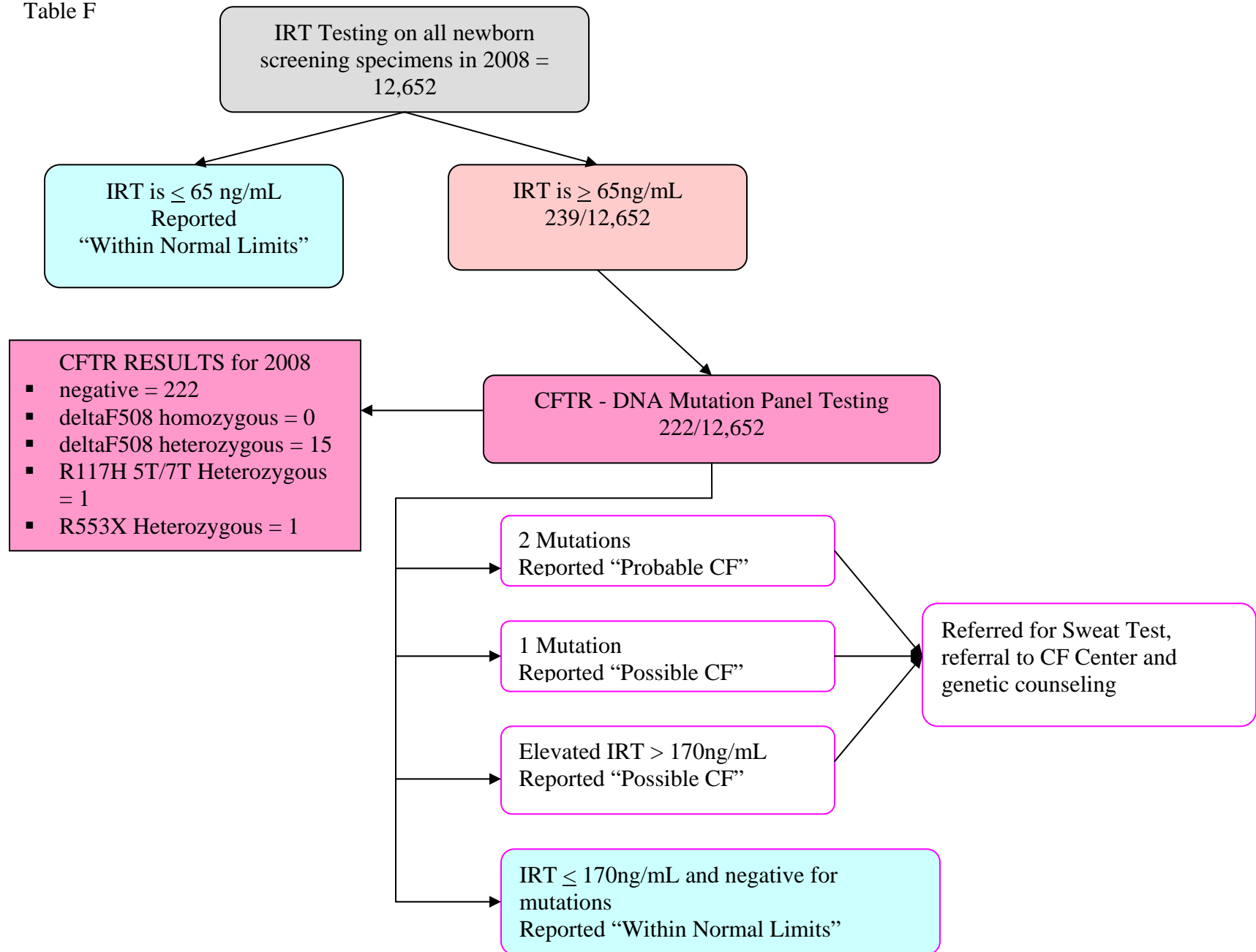
One or more of the following cystic fibrosis symptoms are typical in the first few months of life: slow growth and failure to thrive; recurrent respiratory infections, including respiratory syncytial virus (RSV); salty sweat; malnutrition and frequent runny stools. In 15-20% of cases, meconium ileus (a congenital intestinal obstruction by thickened viscous meconium) will be present in the first days of life. In hot environments, persons with cystic fibrosis can dehydrate and develop life-threatening electrolyte imbalance.

Cystic Fibrosis prevalence rates at birth differ widely across race/ethnicity groups as do the types of mutations that cause the disease. The South Dakota expected prevalence rate is 1 in 3,000 births. In South Dakota, newborn screening dried blood spots are tested for immunoreactive trypsinogen (IRT). (n = 12,652 in 2008) Newborns with IRT values greater than 65 ng/mL (n = 234 in 2008) will have their newborn screening dried blood spots tested for the presence of 23 different CFTR mutations. Newborns with low IRT values or zero mutations are deemed to be screen negative for cystic fibrosis (n = 222 in 2008). Those with one mutation found are reported as possible CF (n = 17 in 2008). Those with two mutations are reported as probable CF (n = 0 in 2008). Both are referred to a Cystic Fibrosis Center for sweat chloride, clinical evaluation, and genetic counseling. (Table F)



A review of the benefits of newborn screening for cystic fibrosis can be found on the CDC website (<http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5313a1.htm>).

Table F



## Newborn Screening Specimen Collection Data

The SDNSP uses standards developed by the Clinical and Laboratory Standards Institute for blood collection on filter paper specifically for newborn screening: *Clinical and Laboratory Standards Institute (CLSI, formerly NCCLS) Blood Collection on Filter Paper for Newborn Screening Programs; Approved Standard - 5<sup>th</sup> Edition*. The primary goal of this standard is to ensure the quality of blood spots collected from newborns. Newborn screening specimens that are unacceptable for testing place an unnecessary burden on the submitting facility, unnecessary trauma to the infant, anxiety to the infant’s parents, and may contribute to the delay in detection and treatment of affected infants. When an unacceptable specimen is submitted, the contracted laboratory (University of Iowa Hygienic Laboratory - UHL) notifies the submitting birth facility to obtain another specimen and reports “poor quality” on the laboratory report.

In 2008, 129 of 13,270 newborn screening specimens were deemed unacceptable for testing. All newborn screening results that were reported “poor quality” were followed to ensure the primary care provider was informed and an acceptable specimen was collected.

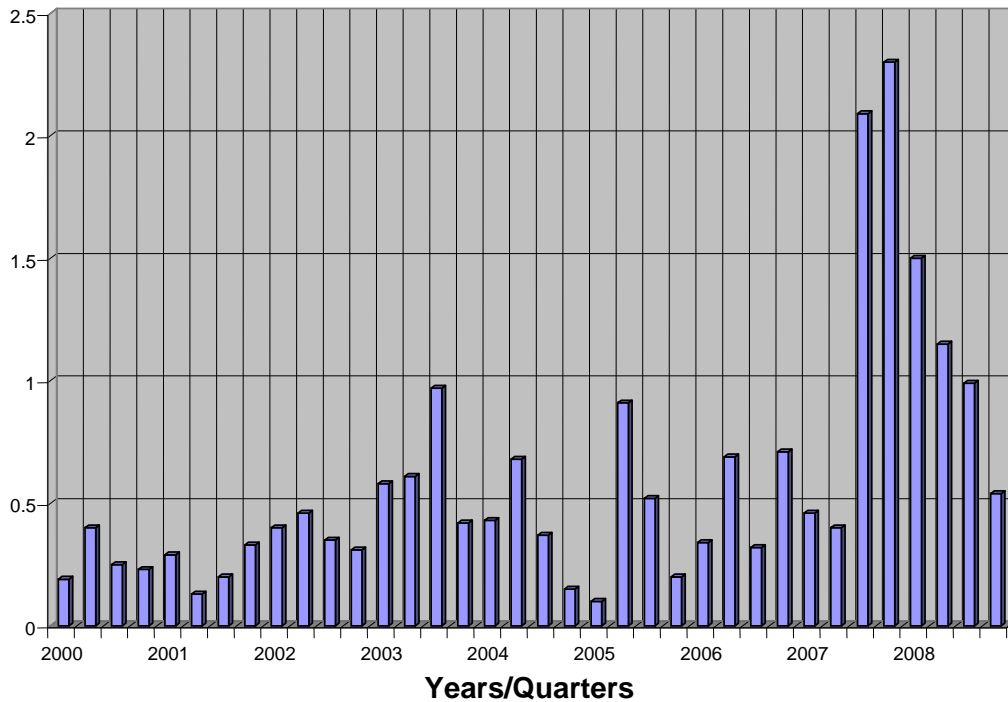
The SDNSP program’s quality assurance goal of unacceptable specimens is less than 1% statewide. Twice a year, *Unacceptable Specimen Reports* are sent to submitting facilities across the state. This report indicates how the facility compared statewide with the number of specimens submitted for testing, the number of unacceptable specimens, the percentage, and the reasons why specimens were rejected for reporting test results. (Table G)

**Table G. South Dakota Newborn Screening Unacceptable Specimens Data, 2008**

<b>Number of specimens unacceptable/Total number of specimens</b>	<b>129/13,270</b>	<b>.98% of submitted specimens statewide</b>
Reasons specimens were UNACCEPTABLE	Number	% of unacceptable
▪ Didn’t soak through	19	15%
▪ Quantity not sufficient	30	23%
▪ Layer or clotted	64	50%
▪ Contaminated	5	4%
▪ Applied to both sides	1	<1%
▪ Serum separated	1	<1%
▪ Paper scratched	4	3%
▪ Other	4	3%

In 2007, the SDNSP experienced a significant rise in unacceptable specimen rates across the state to 2.3%. (Table H) The rate increase occurred with the transition to a new contract laboratory with new processes for reporting and tracking unacceptable specimens. To address the increased rate, the program purchased 10 APHL Clinical and Laboratory Standards Institute Kits for distribution on a loan basis. Birthing facilities with high unacceptable specimen percentages were targeted for distribution. The SDNSP provides technical assistance to birthing facilities based on need and/or request. The contracted laboratory will provide on site training per program request. UHL has developed a Power Point presentation and videos for facilities to use for training new staff. As of April 2009, the SDNSP statewide unacceptable rate is 0.5%. All initial unacceptable specimens are followed up to ensure an acceptable newborn screening specimen is collected. In 2008, there were 126 infants with initial unacceptable specimens – were recollected with no infants lost to follow-up.

**Table H. South Dakota Newborn Screening Unacceptable Specimens Rate, 2000-2008**

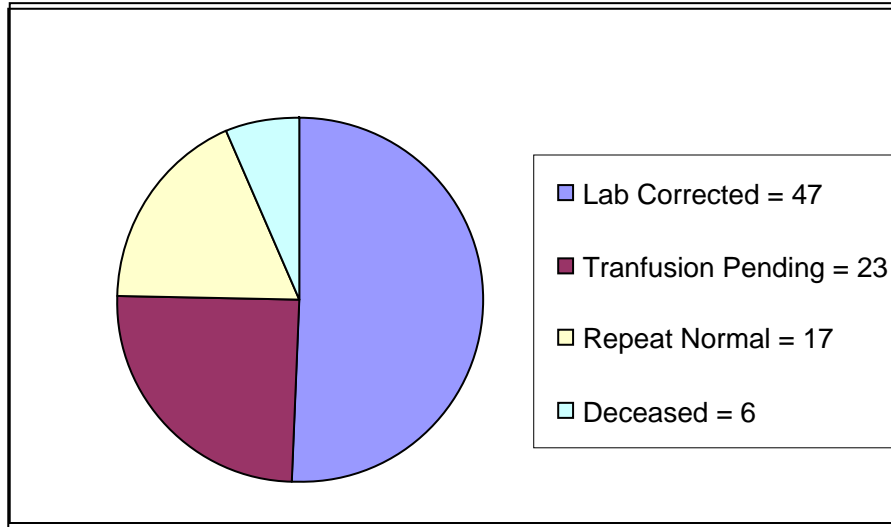


The preferred time of newborn screening specimen collection is 24-48 hours of age. Newborn screening specimens collected prior to 24 hours of age must have a second newborn screening specimen collected. A birth facility should report to the program any infant who is discharged prior to 24 hours of age without a newborn screening specimen collected.

Regardless of the infant's age, the appropriate strategy is always to collect a newborn screening specimen before any transfusion. Hemoglobinopathy, galactosemia and biotinidase screen results are not affected by age at collection.

The contract laboratory depends on the information submitted on the newborn screening specimen collection card to be accurate and entered completely. If the contracted laboratory receives specimen forms with inaccurate or missing information, a fax is sent to the submitting facility requesting additional information. The submitting facility contact is asked to correct and complete the information and fax it back to the newborn screening laboratory. This often delays the time it takes to get the screening results. Also, all the information on the specimen collection form must be entered and is critical to the interpretation and reporting of the results. (Table I)

**Table I. South Dakota Newborn Screening Specimens Collected Early, 2008**  
(<24 hours of age)

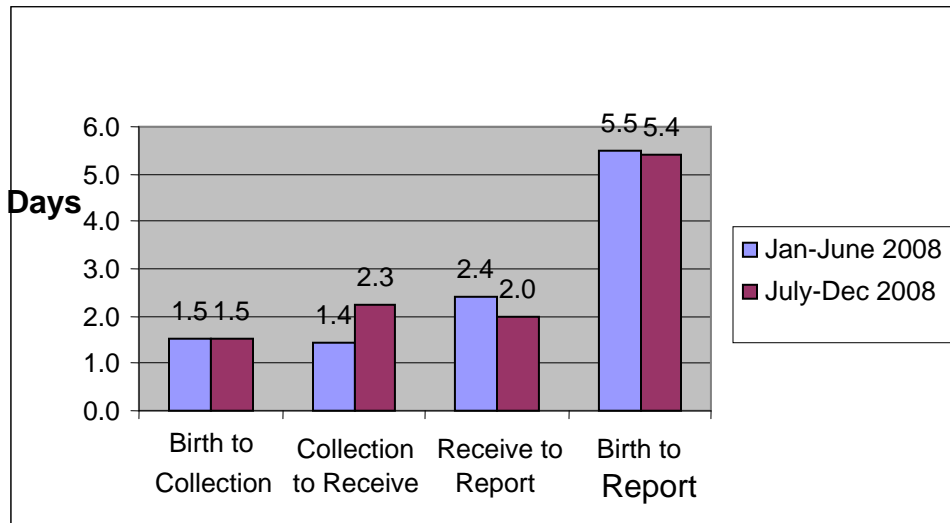


Educational materials regarding newborn screening specimen collection are available to submitting birth facilities. The educational materials include a video on specimen collection and a Power Point presentation. Upon SDNSP request, the University of Iowa Hygienic Laboratory staff will provide on-site education and training sessions.

**Newborn Screening Specimen Turnaround Time**

Regular monitoring of turn-around time between birth and reporting of initial specimen results is an important measure of the newborn screening process. Turnaround time is an indicator of the ability to test specimens and report results to the physician for early identification and treatment of affected infants. The following graph identifies statewide average specimen turn-around times for 2008.

**Table J. South Dakota Newborn Screening Specimen Turnaround Time, 2008**



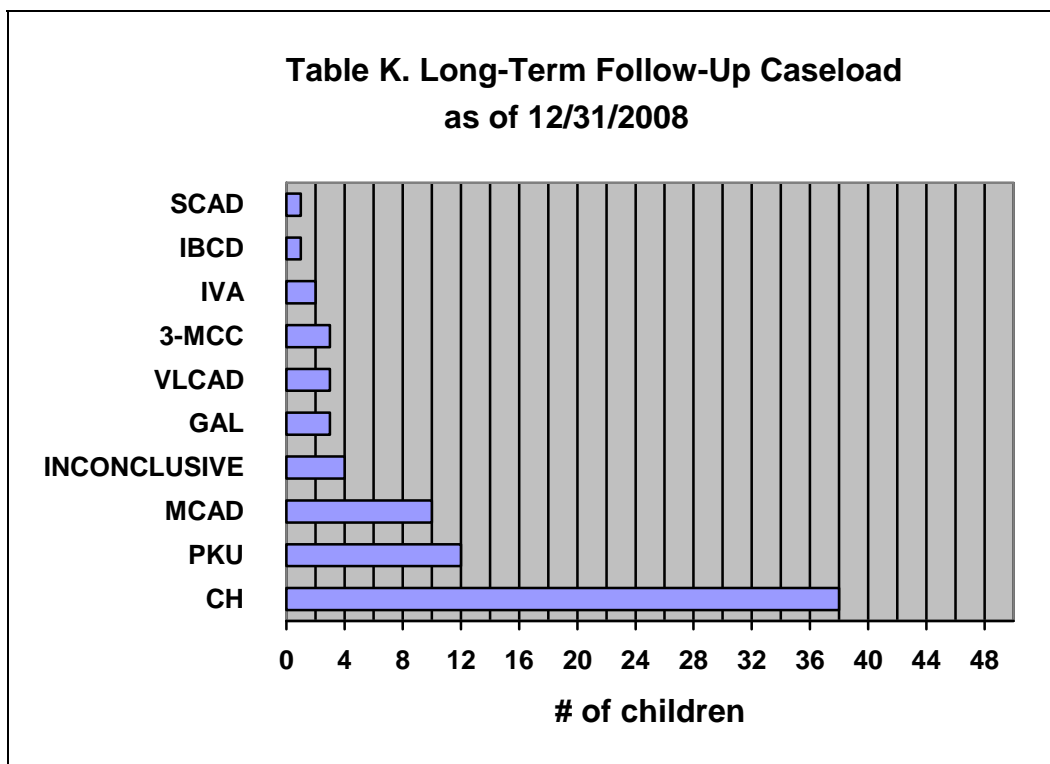
### Long-Term Follow-Up - A Year of Progress

South Dakota Newborn Metabolic Statute 34-24-24 states, “It shall be the responsibility of the department of health to follow the development of all children carrying the syndrome of any metabolic disease to ensure that those persons responsible for the care of the child are fully informed of accepted medical procedures for the detection, prevention, and treatment of such condition.”

To comply with the statute, the South Dakota Department of Health began to develop a Metabolic Long-Term Follow-Up Program in November 2007. Long-term follow-up consists of four components: database/registry, education, care-coordination, and data collection.

A **database/registry** was established in March 2008. It tracks every child in South Dakota with a diagnosed metabolic disorder and records (Table K) the person(s) responsible for the child’s care, the child’s functional abilities and health status and the child’s use of appropriate follow-up services. The database is divided into four sections

1. LTFU – includes the child’s birth information, diagnosis, and contact information for the caregiver, primary care provider and specialty provider.
2. Medical – includes the child’s latest appointment information and management of the disorder. This data is taken from the appointment form completed by the primary care provider and/or specialty provider.
3. Developmental – includes the child’s physical and cognitive abilities. This data is taken from the developmental progress form completed by the primary care provider and/or specialty provider.
4. Contacts – documents communication with caregivers and providers.



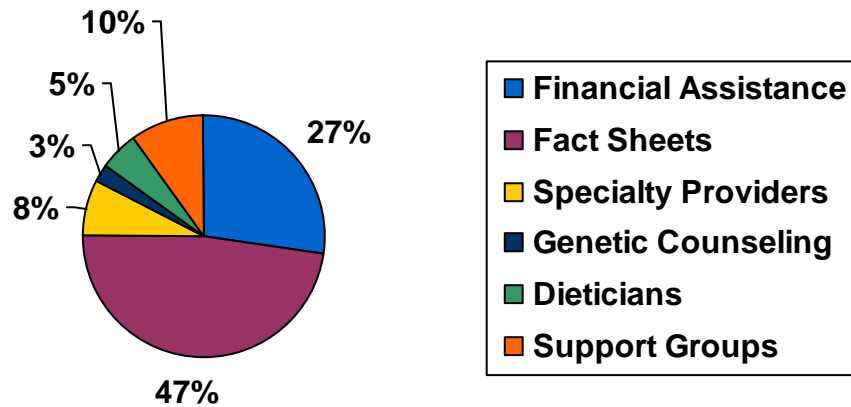
**Education** regarding the appropriate medical management of the disorder is provided to the caregiver upon request. When the initial contact is made with the parent/caregiver, a questionnaire is included. The parent/caregiver can request fact sheets regarding the disorder, assistance locating specialty providers, genetic counseling services, and dietitians, and

information regarding support groups/services and financial assistance. As of 12/31/2008, 71 questionnaires have been mailed out. Of these, 43 have been returned. (Table L)

Information requested has consisted of the following:

- financial assistance - 11
- fact sheets - 19
- locating specialty providers -3
- locating genetic counseling services -1
- locating dieticians -2
- support groups/services -4

**Table L. Information Requested**



**Care-Coordination** ensures follow through of medical appointments, treatment and other needs that impact the child’s care and condition. For some caregivers, transportation may be an issue. This is often the case with specialty appointments when the physician is located in another part of the state. Information regarding financial assistance can be provided to the caregiver. A primary care provider may not be aware that the child has not been recently seen by the specialty provider. The primary care provider may need to arrange for labs to be drawn at the local clinic and results communicated to the specialty provider.

**Data Collection** includes information regarding the child’s most recent appointments, health status and developmental progress. The data is obtained by sending the primary care provider and/or specialty provider the appointment form and developmental progress form at least annually. Each form is only one page in length and includes areas to check-off. Very little narrative is required. The information obtained is then entered into the database.

### Contact Information for Newborn Screening

To order newborn screening collection cards and questions regarding courier:  
University of Iowa Hygienic Laboratory 515-725-1631

To order the “Newborn Screening” pamphlets and other educational materials:  
South Dakota Newborn Screening Program 1-800-738-2301

Lucy Fossen, RN, SD Newborn Screening Program Coordinator at 605-773-3361

Terry Disburg, RN, SD Newborn Hearing Screening Program Coordinator, at 605-773-3361

Sarah Groeneveld, RN, SD Metabolic Long-Term Follow-up Nurse, at 605-312-0976

<http://doh.sd.gov/NewbornScreening/>

<http://doh.sd.gov/Hearing/>

### Newborn Hearing Screening Data Summary, 2005-2008

*By Terry Disburg, RN, Newborn Hearing Screening Coordinator  
Office of Family Health, South Dakota Department of Health*

In 2001, the South Dakota Department of Health was awarded a CDC Cooperative Agreement for the Early Hearing, Detection and Intervention (EHDI) Tracking to establish and implement a surveillance and data tracking system which links the data from the three components of the EHDI system - screening, audiologic diagnosis, and early intervention. Continued funding of the EHDI cooperative agreement supports the department’s Newborn Hearing Screening Program activities. Hearing Screening data will be detailed later in the summary.

Hearing loss occurs in approximately 12,000 children nationally each year, which is 3 of every 1,000 births, and if undetected, can result in developmental delays. South Dakota is part of a national initiative called Early Hearing Detection and Intervention (EHDI). EHDI supports the early identification of infants with hearing loss through screening, audiologic and medical evaluation and enrollment in early intervention with family support services when needed.

The Centers for Disease Control and Prevention, the American Academy of Pediatrics, the American Speech-Language-Hearing Association and numerous other organizations all recommend that:

- all newborns will be screened for hearing loss before **1** month of age, preferably before hospital discharge.
- all infants who did not pass both their initial and re-screening will have a diagnostic audiologic and medical evaluation before **3** months of age.
- all infants identified with some degree of hearing loss will begin receiving appropriate early intervention services before **6** months of age.

The Electronic Vital Records Screening System electronically links each infant’s birth certificate with the infant’s metabolic screening results and hearing screening results. The link permits tracking and follow-up to assure necessary re-screenings, medical evaluations and audiological diagnostics are completed.



**South Dakota Newborn Hearing Screening Program Percentage of Infants Screened by Discharge Status, 2005-2008**

	2005	2006	2007	2008
Total # of Births	11,960	12,387	12,815	12,632
% Screened <b>Prior</b> to Hospital Discharge, Before 1 Month of Age	90.51%	95.80%	96.36%	96.69%
% Screened <b>After</b> Hospital Discharge, Before 1 Month of Age	4.15%	.89%	.95%	.49%
Total % Screened Before 1 Month of Age	94.66%	96.69%	97.31%	97.18%
% of Completed Re-screens	61.22%	63.07%	70.95%	70.34%

The South Dakota Newborn Hearing Screening Program (SDNHSP) has seen a steady increase from 2003 to 2008 in the number of infants screened prior to hospital discharge and before 1 month of age. As a result, the program is now focusing on those infants who are in need of a re-screen. The program sends quarterly reports to each birthing facility indicating infants born at the site who were never screened as well as those who did not pass the initial screening and need a re-screening. Facilities are encouraged to make numerous attempts to contact those identified families to have the infant return for a hearing screening. For those infants born in South Dakota but residing in a neighboring state, the SDNHSP sends hearing screening results to the resident's state program and follows up for results from any screenings conducted there. This follow-up system assists with assuring the SDNHSP database is correct and current.

Statewide, there are more than 170 medical clinics and 9 diagnostic audiologists that have the potential of seeing an infant with a possible hearing loss. All of these facilities have received materials and training in data entry on their role with the medical and audiological evaluations for infants who did not pass their first 2 screenings.

The American Academy of Pediatrics recommended the Joint Committee of Infant Hearing (JCIH) separate protocols for NICU and well-infant nurseries. According to the 2007 JCIH position statement, neonates are at risk of having neural hearing loss (auditory neuropathy/auditory dyssynchrony) because there is evidence that neural hearing loss results in adverse communication outcomes. Consequently, the JCIH recommends ABR technology as the only appropriate screening technique for use in the NICU. All NICU's in the state of South Dakota now have ABR equipment in place.

**South Dakota Department of Health – Infectious Disease Surveillance**

**Morbidity Report, 1 January – 31 May 2009**

(provisional numbers) see <http://doh.sd.gov/ID/site.aspx>

	<b>Disease</b>	<b>2009 year- to-date</b>	<b>5-year median</b>	<b>Percent change</b>
<b>Vaccine-Preventable Diseases</b>	Diphtheria	0	0	n/a
	Tetanus	0	0	n/a
	Pertussis	9	12	-25%
	Poliomyelitis	0	0	n/a
	Measles	0	0	n/a
	Mumps	1	0	+100%
	Rubella	0	0	n/a
	<i>Haemophilus influenzae</i> type b	0	0	n/a
<b>Sexually Transmitted Infections and Blood-borne Diseases</b>	HIV infection	7	14	-50%
	Hepatitis B, acute	1	0	+100%
	Chlamydia	1238	1094	+13%
	Gonorrhea	168	107	+57%
	Syphilis, early	2	2	0%
<b>Tuberculosis</b>	Tuberculosis	3	5	-40%
<b>Invasive Bacterial Diseases</b>	<i>Neisseria meningitidis</i>	2	2	0%
	Invasive Group A <i>Streptococcus</i>	15	8	+88%
<b>Enteric Diseases</b>	<i>E. coli</i> , Shiga toxin-producing	2	4	-50%
	Campylobacteriosis	76	68	+12%
	Salmonellosis	97	46	+111%
	Shigellosis	2	19	-89%
	Giardiasis	24	29	-17%
	Cryptosporidiosis	41	19	+116%
	Hepatitis A	1	2	-100%
<b>Vector-borne Diseases</b>	Animal Rabies	19	21	-10%
	Tularemia	0	2	-100%
	Rocky Mountain Spotted Fever	0	1	-100%
	Malaria (imported)	1	0	+100%
	Hantavirus Pulmonary Syndrome	0	0	0%
	Lyme disease	1	0	+100%
	West Nile Virus disease	0	0	0%
<b>Other Diseases</b>	Legionellosis	0	1	-100%
	<i>Streptococcus pneumoniae</i> , drug-resistant	2	1	+100%
	Additionally, the following were reported: Chicken Pox: (34) Group B <i>Strep</i> , invasive (11); Hepatitis B, chronic (3); Hepatitis C, chronic (59); MRSA, invasive (34); Strep Pneumo < 5, (4); Typhoid, (2)			

Communicable diseases are obligatorily reportable by physicians, hospitals, laboratories, and institutions.

The **Reportable Diseases List** is found at <http://doh.sd.gov/Disease/report.aspx> or upon request.

Diseases are reportable by telephone, mail, fax, website or courier.

**Secure website:** [www.state.sd.us/doh/diseasereport.htm](http://www.state.sd.us/doh/diseasereport.htm).

**Telephones:** 24 hour answering device 1-800-592-1804; for a live person at any time call 1-800-592-1861; after hours emergency 605-280-4810. **Fax** 605-773-5509.

**Mail** in a sealed envelope addressed to the DOH, Office of Disease Prevention, 615 E. 4th Street, Pierre, SD 57501, marked "Confidential Medical Report".

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