Birth Defects Program

2005 Annual Report

MINNESOTA MDH DEPARTMENT OF HEALTH

Environmental Impacts Analysis Unit

June 2006

Intentionally Left Blank

Summary

The Birth Defects program began active surveillance on June 1, 2005. Due to the time lag in records being available for review after the birth of a child, site visits for abstraction began in August 2005. The data collected by the abstractors is entered into the Birth Defects Information System (BDIS) database. After review, a final birth defect code is assigned. The children are then referred to the Minnesota Children With Special Health Needs (MCSHN) program for referral to services such as Medical Assistance (MA), specialty clinics, local public health, etc. Specifics including: estimates of the number of birth defects in Minnesota from birth certificate data; actual numbers of validated birth defect cases at selected hospitals in Minnesota from active surveillance data; and the number of children referred for services are included in this document as well as background information on the Minnesota Birth Defects program.

Intentionally Left Blank

Table of Contents

Intentionally Left Blank

Introduction

Effective March of 2005, the State of Minnesota statutory language (MS144.2215-2219) authorized the Minnesota Department of Health (MDH) to collect birth defect information. This statute did not include financial support for Birth Defects program activities. MDH's Birth Defects program is primarily funded by a five-year non-competing grant from the Centers for Disease Control and Prevention (CDC) in the amount of $110,000 per year. The Birth Defects program also receives in-kind contributions through collaborations with the following MDH programs:

- Fetal Alcohol Syndrome (FAS)
- Genomics Program
- Minnesota Children with Special Health Needs (MCSHN)
- Newborn Screening (NBS)
- Newborn Hearing and Screening (NHS)

as well as the following Non-MDH collaborators:

- Birth Defects Work Group (an advisory work group)
- Some Specialty Physicians (for coding purposes)
- Folic Acid Council (FAC)
- Iowa Birth Defects Registry
- Local Public Health
- March of Dimes (MOD)
- Mayo Clinic of Rochester
- National Birth Defects Prevention Network (NBDPN)
- University of Minnesota

As the program becomes more established, additional collaborating partners will be recruited and additional funding sources explored.

Data Collection

The Minnesota Department of Health's (MDH) Birth Defects program began active surveillance on June 1, 2005. Due to the time lag in records being available for review after the birth of a child, site visits for abstraction began in August 2005. Although the two full-time abstractors work at all facilities, an individual primary contact has been established for each location. As of January 1, 2006, a total of 333 records have been reviewed, resulting in 166 validated birth defects cases, 154 of which were referred to MCSHN. During the start-up period, we did not collect data from all of the targeted hospitals. Therefore, these totals do not reflect the projected number of birth defects that will be collected in a full year of abstracting. Future reports will include a detailed description of the birth defects collected.

After the abstractors enter the data into the Birth Defects Information System (BDIS) database, the Public Health Nurse lead worker validates the birth defect cases and assigns a final code to each birth defect. The Birth Defects program uses the Minnesota Birth Defects Coding List (Appendix A). Conditions include 44 nationally reported birth defects and 1 additional code (single ventricle) was added at the recommendation of a collaborating physician. The list of nationally reported birth defects was developed collaboratively by the Centers for Disease Control and Prevention (CDC) program and the National Birth Defects Prevention Network (NBDPN). Each validated birth defect case is then sent a letter (Appendix B) from the Birth Defects program, which explains the opt-out option. Included with the letter are: the fact sheet, "Birth Defects – What is Being Done in Minnesota?" (Appendix C); a brochure provided by the

MCSHN program which describes services available (Appendix D); and a Birth Defects Opt-Out Form (Appendix E). The Birth Defects Opt-Out Form can be filled out and returned to the Birth Defects program if parents do not want their child's information included in the BDIS database ("opt-out"). If an individual would like to "opt-out" of the system, their personal identifying information will be removed from the BDIS once the Birth Defects program receives their completed opt-out form. A letter is then sent to the family acknowledging that the form was received and personal identifying information has been removed from the BDIS database.

The Birth Defects Program collaborates with the Minnesota Fetal Alcohol Syndrome (FAS) program and receives some funding from their program. The FAS Prevention program case definition for FAS is broader than the NBDPN case definition used for Minnesota's Birth Defects Information System (BDIS) database. All FAS data collected by the abstractors are also validated using the CDC "FASSLink" program to meet the FAS program's grant objectives.

Data Sources for Case-Finding

Currently, the Birth Certificate and Hospital Discharge Summary data are being used in addition to active surveillance for case finding. Eventually, the Birth Defects program will use all of the listed sources for case finding.

- Fetal Death Records
- Birth Certificates
- Death Certificates for Infants
- Department of Human Services Medical Assistance Provider Encounter data
- Hospital Discharge Summaries
- Electronic Medical Records (at hospitals where available)

Since fetal death records, birth certificates, and infant death records are not created for the purpose of surveillance, it is important to evaluate the validity and accuracy of the birth defect data they provide. Appendix F lists the total number of each birth defect in Minnesota as listed on the Minnesota birth certificate. Appendix G provides the rate of birth defects per 10,000 births in Minnesota. Birth certificates are not a very accurate source for birth defect data; therefore a high confidence should not be placed in these figures to represent the actual rates of birth defects in the state of Minnesota.

As part of our ongoing evaluation of passive data sets for use in birth defect surveillance, data from the Minnesota Hospital Discharge Database (MnHDD) from 2002 and 2003 were examined. This was part of a Master's Thesis project conducted under the mentoring of Dr. Myron Falken. The MnHDD was searched for all occurrences of an ICD-9 code corresponding to a birth defect and was analyzed to identify possible duplicates in the de-identified data. Duplicates result from a child being seen multiple times and a new discharge record is generated for each visit. A process was created to eliminate likely duplicates. An entry was identified as a duplicate if it had the same date of birth, county of residence, ICD-9 code, and the "discharged from" field for one facility matched the "admit date" at another facility. The de-duplicated data at one facility was compared to the known cases at that facility; 93% of potential duplicates were determined to be real duplicates and not unique cases. Likely duplicate entries for the same child were eliminated to estimate a case count.

This study also provided information useful for case finding. Over 50% of birth defects were coded in the first or second position for inpatient visits, and over 80% for outpatient visits. Defects easily recognizable at birth were most frequently diagnosed at the birthing hospital, and the most severe defects had the highest frequency of repeat visits. Overall, the MnHDD was found to be useful for case finding, however, it cannot be used for patient referrals because the data is greater than one year old.

Progress on Hospital Abstraction

The Birth Defects program has gained access to records in all eight locations targeted for abstraction in the first year of active surveillance (Table 1). By 2007, the Birth Defects program's goal is to abstract at all hospitals in Hennepin and Ramsey counties. This will capture approximately fifty percent of all births in Minnesota. The program also plans on abstracting at all hospital Neonatal Intensive Care Units (NICUs) statewide.

Table 1: Case Ascertainment as of 1/1/2006

Name	County
Abbott Northwestern Hospital	Hennepin
North Memorial Medical Center	Hennepin
Hennepin County Medical Center	Hennepin
Fairview University Medical Center	Hennepin
Regions Hospital	Ramsey
Children's Hospital and Clinics (Mpls.)	Hennepin
Children's Hospital and Clinics (St. Paul)	Ramsey

The accuracy, completeness and timeliness of the abstraction process underwent an informal evaluation. This was done as part of the creation of an Access database to house the initial birth defects data while the MDH Public Health Laboratory is developing the ORACLE database. The data entry screens and data table architecture were modeled after the abstraction form. There were numerous discussions on data definitions and quality between the data manager and abstraction staff to help ensure efficient operation and data availability. Additional evaluation of the abstraction process will continue to be conducted.

Referral to Services

Minnesota is unique in the relationship of the state health department to the local public agencies located in each of the 87 counties. These agencies are partially funded through the Minnesota Department of Health and are actively involved in setting health priorities throughout the state. These agencies are where most if not all of the actual case management and in some case direct services are provide for public health services. It is therefore very important that these agencies are aware of specific program activities and are encouraged to participate with in the limits of their resources for specific program or projects.

During 2005 Staff from the Birth Defects program met with most Community Health Services (CHS) administrators and Maternal and Child Health (MCH) coordinators of local public health organizations in Minnesota. The purpose of these meetings was to describe the Minnesota Birth Defects Information System (BDIS) and to discuss referral and follow-up activities with each agency. Since each agency differs in both resources and policy it is important to be able to understand how activities differ through out the state. After each meeting birth defects program staff asked if each agency wanted to receive referrals from the program. All of the agencies agreed to accept referrals.

In addition to getting agreement from each agency, birth defects program staff is currently involved in detailed discussion with Hennepin and Ramsey counties on which referrals they would be willing to accept and what types of services or case management they will provide. Discussions are ongoing about the type of information the birth defects program should provide each agency. The birth defects program could provide in depth information about each case or basic information. Those details will be decided during 2006.

Quality Control

Five percent of the 2005 data was randomly selected and reabstracted for quality control purposes. A review of the re-abstracted charts indicated that overall the data collection is of high quality. The data did indicate that not all “not found” check boxes were always documented when information was abstracted. It is important to have each of those boxes verified to be able to confidently determine whether the data is not found or that the item was not assessed. Accuracy is determined using a process to evaluate the major or minor discrepancies entered by each abstractor for each required field that is abstracted from the medical record (see Appendix H for the Birth Defects Validation Study Form). In addition to record reviews, the birth defects program staff have begun the development of a policies and procedure manual and have developed a retention schedule for all of the BDIS records.

In order to make certain that all medical records are reviewed, a records-tracking spreadsheet has been developed. The records-tracking spreadsheet provides information about the case, which includes medical record, date of birth, and date of discharge, as well as other information (see Appendix I). The records-tracking spreadsheet is used to determine the average time between date of birth and discharge date. This time is important, because staff have developed a goal of referring children to MCSHN within 90 days. Preliminary analysis of the data indicates that we are not able to meet this goal with the current process. In addition, the preliminary analysis revealed the need for more information to be entered on the records-tracking spreadsheet. The date the record was abstracted and the date the record was sent for referral to MCSHN need to be included. See Table 2 for details on the average time it takes before the records are available to be abstracted.

Table 2: Days to Birth Defects Referral

Preliminary Data - Days to Birth Defects Referral	
Facility	**Average time from Birth Date to Record Request (Days)**
1	51
2	61
3	86
4	102
5	111
6	116

Additional methods to conduct quality control will include the matching of case records with the birth certificates for each appropriate year. The birth certificates will be also used to determine completeness of our active surveillance system and will be an additional means of case finding. An epidemiologist in the childhood lead poisoning program has developed a matching program. This SAS program performs matching with a manual review of possible matches. The matching will determine which records have potential errors in certain key fields such as name spellings, dates of birth, county of residence, and race. As the system grows, other data sets will be used for quality control and case finding to include medical assistance data and hospital discharge data.

Folic Acid Prevention Activities

At the 2004 Minnesota State Fair, a poster was placed in 87 women's bathrooms promoting folic acid awareness and use. Because it was a public health message and other commercial interests did not purchase the space, this poster was actually kept up all year. For 2005, however, financial constraints limited our ability to display a poster in a similar fashion.

On August 30, 2005, the Birth Defects Program staff manned the MDH booth at the Minnesota State Fair. Throughout the morning, two program staff worked specifically conducting folic acid education. They handed out 250 copies of the CDC brochure, "You May Not be Ready to Have a Baby" and spoke with many people visiting the booth. We utilized the non-contemplator style folic acid message. The staff targeted teenagers and their mothers and discussed the importance of taking a multi-vitamin to meet increased calcium, iron and folic acid requirements for adolescent girls. They also targeted pregnant women and mothers with infants to encourage them to continue to take a multi-vitamin after childbirth. Overall, the crowd was receptive to educational efforts. Additional CDC brochures, "Before you know you're pregnant," were distributed throughout the duration of the fair.

A folic acid education project was developed in the summer of 2005 and was tested with girls (age 10 and 14) to determine if messages were effective and activities were age-appropriate. The girls also did a brief pre-test and post-test to determine if their knowledge about folic acid and other nutrients teens need increased. This will be adapted into a kit for earning a Girl Scout patch.

Current Year Activities

The Birth Defects program is working with the FAC to recruit collaborating partners and pursue educational opportunities. A collaboration with the Minority Health program has been initiated. Because of their connection to families through grief counseling, priests in the Latino community in Minnesota noticed many families with children who died or had birth defects. The clergy approached MDH’s Minority Health contact to discuss their concerns. The Minority Health contact is a member of the FAC. During a FAC meeting, she reported on a project her program was starting with the Latino community and asked if the Birth Defects program could help provide information for their community educators.

Because the Latino community is more receptive to information received from respected leaders in their community, the Birth Defects program provided information through the leaders of the Latino community. One of the goals of the project was to educate several Spanish-speaking leaders of the church about birth defects and the need for daily folic acid intake among women of childbearing age. They in turn educated three individuals from each parish who will educate their parish members on an ongoing basis. In this way, the message can be disseminated to the Latino community through contacts that they respect and trust.

The Birth Defects program will also be creating two displays to be used at various county fairs, health fairs, etc. The displays will provide education about birth defects and promote daily consumption of folic acid. One display will be in English and the other in Spanish. The Minority Health program will be the primary user of the Spanish display for Latino activities. The MCH program is funding the creation and purchase of the Spanish display.

Another collaboration has begun between the Birth Defects program, Shriners Hospitals for Children, and several Specialty Clinics that work with children who have Neural Tube Defects (NTDs). The Birth Defects program is collaborating with these groups to create an NTD Reoccurrence Prevention plan. The goal is to ensure that all mothers who have given birth to children with an NTD receive information about the need to take a higher amount folic acid each day (4 mg/4,000 mcg) at least two months prior to becoming pregnant again.

The Birth Defects program has also submitted an article on birth defects and folic acid consumption to several organizations including the Minnesota Medical Association (MMA).

The article will be included in the electronic newsletter that physicians throughout Minnesota receive. The goal is to encourage physicians to educate and assess their female patients about adequate folic acid consumption during routine health exams.

Last year, the Birth Defects program did not have sufficient funds to purchase ad space for the Minnesota State Fair. This year, the MCH program will be funding a campaign similar to what was done two years ago. A poster will be created with the folic acid message, which will be displayed in the stalls of a number of female restrooms throughout the state fair grounds. This was a very successful project and is a great way to reach women from many cultures and locations throughout Minnesota.

Long-Term Goals

Long-term goals for the Birth Defects program are to:

- Monitor trends of birth defects,
- Accurately target intervention, prevention and services for communities, patients, and their families,
- Inform health professionals of the risks for birth defects, and
- Participate in scientific investigations of potential causes of birth defects and ways to prevention them.

The Birth Defects program hopes to eventually serve all of the children in Minnesota who have a birth defect—in both metro and greater Minnesota. The goal is to ensure that families receive adequate follow-up services and education that will not only help them care for their child's special needs, but will provide them with the information needed to plan for future children if so desired. In the future the Minnesota Birth Defects program hopes to provide the women of Minnesota with the tools and knowledge necessary to avoid preventable birth defects and protect future generations of children in Minnesota.

Intentionally Left Blank

Appendices

Intentionally Left Blank

APPENDIX A – Minnesota Birth Defects Coding List

Intentionally Left Blank

ICD-9 Codes of the 44 Nationally Reported Birth Defects Collected in Minnesota

Central Nervous System	
Anencephalus	740.0-740.1
Spina Bifida Without Anencephalus	741.0-741.9, w/o 740.0-740.10
Hydrocephalus Without Spina Bifida	742.3 w/o 741.0,741.9
Encephalocele	742.0
Microcephalus	742.1
Eye	
Anophthalmia/Microphthalmia	743.03,743.1
Congenital Cataract	743.30-743.34
Aniridia	743.45
Ear	
Anotia/Microtia	744.01, 744.23
Cardiovascular	
Common Truncus	745.0
Transposition of Great Arteries	745.10,.11,.12,.19
Tetralogy of Fallot	745.2
Ventricular Septal Defect	745.4
Atrial Septal Defect (Include only if estimated gestational age is greater than or equal to 36 weeks)	745.5
Endocardial Cushion Defect	745.60,.61,.69
Pulmonary Valve Atresia and Stenosis	746.01,746.02
Tricuspid Valve Atresia and Stenosis	746.1
Ebstein’s Anomaly	746.2
Aortic Valve Stenosis	746.3
Hypoplastic Left Heart Syndrome	746.7
Patent Ductus Arteriosus (Include only if estimated gestational age is greater than or equal to 36 weeks)	747.0
Coarctation of Aorta	747.10

Orofacial	
Cleft Palate Without Cleft Lip	749.0
Cleft Lip With and Without Cleft Palate	749.1,749.2
Choanal Atresia	748.0
Gastrointestinal	
Esophageal Atresia/Tracheoesophageal Fistula	750.3
Rectal and Large Intestinal Atresia/Stenosis	751.2
Pyloric Stenosis	750.5
Hirshsprung’s Disease (Congenital Megacolon)	751.3
Biliary Atresia	751.61
Genitourinary	
Renal Agenesis/Hypoplasia	753.0
Bladder Exstrophy	753.5
Obstructive Genitourinary Defect	753.2,753.6
Hypospadias and Epispadias	752.61,752.62
Musculoskeletal	
Reduction Deformity, Upper Limbs	755.20-755.29
Reduction Deformity, Lower Limbs	755.30-755.39
Gastroschisis	756.79
Omphalocele	756.79
Congenital Hip Dislocation	754.30,.31,.35
Diaphragmatic Hernia	756.6
Chromosomal	
Trisomy 13	758.1
Down Syndrome	758.0
Trisomy 18	758.2
Other *	
Fetal Alcohol Syndrome	760.71

Non-Nationally Reported Birth Defect to Collect:

Single Ventricle 745.3

APPENDIX B – Parent Letters

Intentionally Left Blank

This letter is sent to the parents
of all abstracted children, except
deceased children and those with
Fetal Alcohol Syndrome (FAS).

Date

The Parent(s) of «FirstName» «LastName»
«Address»
«City», «State» «Zip_Code»

Dear Parent(s):

The Minnesota Department of Health would like to congratulate you on the birth of your baby!

Our goal is to help all children thrive, grow, and be as healthy as possible. We understand that your baby may have special health needs. Finding help for your baby can be overwhelming. We have enclosed information from MDH's Minnesota Children With Special Health Needs program that may be useful to you and your family.

We gather data about babies born each year with certain health conditions (some minor, others serious) diagnosed in the first year of life. This helps us look for causes of these conditions. It may also help us prevent them in the future. Data privacy laws strictly protect the information that we gather. You have the right to remove all data that identify you or your child from our records. If you choose to remove identifying data, you must sign the enclosed form and return it to us.

Having your identifying information allows us to contact you about services that may be helpful to you. If you remove your identifying information, state law requires we inform you that our program can no longer contact you about services and resources that may benefit you and your family.

If you have questions about the data that we collect, please call Myron Falken at (651) 201-4898. For all other questions, please call Maureen Alms at (651) 201-4892.

Best wishes to you and your family.

Sincerely,

John Linc Stine, Director
Environmental Health Division
P.O. Box 64975
St. Paul, Minnesota 55164-0975

JLS:BB:rlk
Enclosures

Intentionally Left Blank

This letter is sent to the parents of all
abstracted children who are deceased.

Date

The Parent(s) of «FirstName» «LastName»
«Address»
«City», «State» «Zip_Code»

Dear Parent(s):

We understand that you have recently lost a child and extend our sympathies to you and your family. The Minnesota Department of Health gathers data about babies born each year with certain health conditions diagnosed in the first year of life. This helps us look for causes of these conditions. It may also help us prevent them in the future.

Your child had one of the conditions on which we collect data. Data privacy laws strictly protect the information that we gather. You have the right to remove all data that identify you or your child from our records. If you choose to remove identifying data, you must sign the enclosed form and return it to us. If you choose to have your identifying information remain, we will continue to offer you services and resources that may benefit you and your family.

If you have questions about the data that we collect, please call Myron Falken at (651) 201-4898. For all other questions, please call Maureen Alms at (651) 201-4892.

Best wishes to you and your family.

Sincerely,

John Linc Stine, Director
Environmental Health Division
P.O. Box 64975
St. Paul, Minnesota 55164-0975

JLS:BB:rlk
Enclosures

Intentionally Left Blank

This letter is sent to the parents
of all abstracted children with
Fetal Alcohol Syndrome (FAS).

Date

The Parent(s) of «FirstName» «LastName»
«Address»
«City», «State» «Zip_Code»

Dear Parent(s):

The Minnesota Department of Health's (MDH) goal is to help all children thrive, grow, and be as healthy as possible.

We understand that your child was born with special health needs. Finding help for your child can be overwhelming. We have enclosed information from MDH's Minnesota Children With Special Health Needs program that may be useful to you and your family.

We gather data about children born each year with certain health conditions. This helps us look for causes of these conditions. It may also help us prevent them in the future. Data privacy laws strictly protect the information that we gather. You have the right to remove all data that identify you or your child from our records. If you choose to remove identifying data, you must sign the enclosed form and return it to us.

Having your identifying information allows us to contact you about services that may be helpful to you. If you remove your identifying information, state law requires we inform you that our program can no longer contact you about services and resources that may benefit you and your family.

If you have questions about the data that we collect, please call Myron Falken at (651) 201-4898. For all other questions, please call Maureen Alms at (651) 201-4892.

Best wishes to you and your family.

Sincerely,

John Linc Stine, Director
Environmental Health Division
P.O. Box 64975
St. Paul, Minnesota 55164-0975

JLS:BB:rlk
Enclosures

Intentionally Left Blank

APPENDIX C – Birth Defects Program Fact Sheet

Intentionally Left Blank

Minnesota Department of Health Fact Sheet

Birth Defects – What is Being Done in Minnesota?

What causes birth defects?

Little is known about the actual causes of birth defects. Approximately twenty percent of birth defects may be attributed to genetic factors. Ten percent are attributed to environmental factors, including drug or alcohol abuse, infections, or exposure to certain medications or other chemicals. The causes of the remaining seventy percent are currently unknown.

What is the Minnesota Birth Defects Program and what are its goals?

The Birth Defects Program is a new activity at the Minnesota Department of Health (MDH). This program gathers data about babies born each year with certain health conditions diagnosed within the first year of life. The mission of the program is to help children thrive, grow, and be as healthy as possible. The primary goals of the Birth Defects Program are to:

- Monitor incidence trends of birth defects to detect emerging health concerns and identify affected populations,
- Ensure appropriate services are provided to affected families,
- Prevent birth defects through targeted education,
- Educate physicians and the public regarding birth defects, and
- Stimulate research on risk factors, treatment, prevention, and the cure of birth defects.

How does the Birth Defects Program benefit Minnesota?

There are many programs in our state that may benefit children with birth defects and their families. Knowledge of the occurrence of birth defects will help the MDH link families to the services they need. Better tracking of when and where birth defects occur and potential links to environmental factors will provide critical information that may help prevent birth defects in the future. This information will help all children have the best possible start in life.

What if parents don't want MDH to have their personal identifying information?

Data privacy laws strictly protect the information that the Birth Defects Program gathers. If, for any reason, parents want to exclude their child from the system, they can fill out a form and the personal identifying information on that child will be removed. The Birth Defects Program will no longer contact you regarding services for that child. This does not eliminate the possibility that another program within MDH will contact you. They may have your information from another source.

Where can I get additional information?

The MDH maintains a website for birth defects information at the state level. It contains background information on current and past activities, an overview of the current advisory work group, fact sheets on medications that are known to cause birth defects, links to Minnesota statutes and other helpful websites. The web page is at:

http://www.health.state.mn.us/divs/eh/birthdefects

For more information about birth defects, or if you require this document in another format such as large print, Braille, or cassette tape, contact the Birth Defects Program at:

651-201-5000 or 1-800-657-3908

MDH TDD/TTY at: 651-201-5797
MN Relay Service at: 1-800-627-3529

MINNESOTA MDH DEPARTMENT OF HEALTH
Environmental Health Division
Environmental Surveillance and Assessment Section
Environmental Impact Analysis Unit – Birth Defects Program
625 Robert Street North, P.O. Box 64975
St. Paul, MN 55164-0975
12/01/2005
Printed on Recycled Paper

Intentionally Left Blank

APPENDIX D – MCSHN Program Brochure

Intentionally Left Blank

This brochure is sent to the parents of all abstracted children, except deceased children and those with Fetal Alcohol Syndrome (FAS).

Team Clinics:

Children who have chronic health conditions, including birth defects, can benefit from being in contact with specialists who work together in developing care plans. There are Team Clinics at the major medical centers in Minnesota as well as some that are located outside the cities of St. Paul and Minneapolis. MCSHN can assist in identifying a team clinic for you to consider for your child.

Dental Law for Cleft Lip and/or Palate:

In Minnesota there are two laws that cover children born with cleft lips and/or palates. If the cleft has caused problems with the child's dental development, and the family has both private medical and dental insurance, the medical insurance can be billed once the dental insurance has paid what it will.

The second law states that children with clefts can be covered by their parent's insurance until age 25 if they are enrolled as a full-time student in a post-secondary program such as college or a technical school.

To locate services in your community go to:
http://www.health.state.mn.us/mcshn and click on "Early Childhood Intervention" or call
toll free: 1-800-728-5420
Metro: 651-215-8956

Don't Speak English?

People who speak little or no English can reach someone who speaks their language (live or voice mail) to help them access early childhood programs and services.

There is no cost to use these lines.

Multilingual Human Services Referrals:

Arabic	(800) 358-0377
Hmong	(888) 486-8377
Khmer (Cambodian)	(888) 468-3787
Lao	(888) 487-8251
Oromo	(888) 234-3798
Russian	(888) 562-5877
Serbo-Croatian (Bosnian)	(888) 234-3785
Somali	(888) 547-8829
Spanish	(888) 428-3438
Vietnamese	(888) 554-8759

MCSHN

85 East Seventh Place
P.O. Box 64882
St. Paul, MN 55164-0882

Upon request, this publication can be made available in alternate forms, such as large print, or audiotape.

♻ *Printed on recycled paper.*

5/05

MCSHN

Health Resources for Your Child

The information in this brochure briefly describes some of the services that might be helpful to you and your new baby.

The Minnesota Children with Special Health Needs (MCSHN) Information and Assistance Line

Toll free: 1-800-728-5420
Metro area: 651-215-8956

MINNESOTA MDH DEPARTMENT OF HEALTH

This brochure is sent to the parents of all abstracted children, except deceased children and those with Fetal Alcohol Syndrome (FAS).

How Can MCSHN Help You?

Early Childhood Programs

Early Intervention Services (Part C):

Early intervention services are available in every community to children with disabilities or other health conditions that hinder a child's development. Parents and professionals decide together which services the child and family needs.

Follow Along Program:

The Follow Along Program is a free program that helps families understand and learn about their child's health and development. It is an easy way to find out about other services available for your child.

Financial Assistance

Medical Assistance (MA/Medicaid):

Medical Assistance is Minnesota's program to help people who have a low income with the cost of medical care. Eligibility is decided based upon family size and income.

Pregnant women and babies and toddlers under the age of two years are eligible at a higher income level than children ages two to eighteen years of age. Minnesota Children with Special Health Needs can help you decide whether or not you may qualify for MA.

It is important that applications be completed and returned as soon as possible so that you get the most coverage for any medical costs.

TEFRA Option:

The TEFRA option gives MA to certain children with disabilities or long-term health conditions who live at home with their families, but whose families are above-income for MA.

The State Medical Review Team (SMRT) determines medical eligibility for TEFRA .

MinnesotaCare:

MinnesotaCare is a subsidized health care program for people who live in Minnesota and do not have access to health insurance. There are no health condition barriers, but applicants must meet income and program guidelines to qualify. There are either annual or monthly premiums to pay depending on the family's income. There also may be co-pays.

Home and Community Based Waivered Services:

There are seven different types of waivered services that may be available for children and adults in Minnesota who have a chronic illness or disability. The waivers are designed to assist families in caring for their ill or disabled family member at home.

Access to waivered services is through the local county family or human services department.

Supplemental Security Income (SSI):

SSI may be an additional source of money to assist with a child's special needs. There are both income and medical eligibility criteria that must be met. Children who are eligible both financially and medically for SSI are also eligible to apply for MA and food stamps.

Minnesota Comprehensive Association (MCHA):

This is health insurance for Minnesota residents who have been turned down for health insurance by the private market, due to pre-existing health conditions.

Miscellaneous Financial Help:

It is possible that your child might receive help with prescription drug coverage, glasses, and eye examinations.

Specialized Care

Public Health Home Visiting:

Home visiting goals include promoting family self-sufficiency and improving the health and well-being of Minnesota children and families.

Primary Care/Medical Home: Do You Have One?

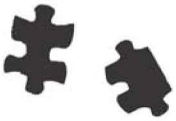
A "medical home" is a way to provide high quality primary health care for children with special health needs. It is health care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally competent.

This fact sheet is sent to the parents of all abstracted children with Fetal Alcohol Syndrome (FAS).

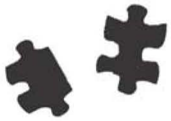
Minnesota Department of Health

Minnesota Children with Special Health Needs (MCSHN)

www.health.state.mn.us/mcshn



Need Help Piecing Together Services for a Child with Special Health Needs?



Call: 651-215-8956 or 1-800-728-5420

The Minnesota Children with Special Health Needs (MCSHN) Information and Referral Line can link you with agencies in your area that provide the services you need.

Finding necessary services for children with special health needs can be a puzzling job. The **MCSHN Information and Referral Line** can help you find the right resources to meet special needs. The service is free and confidential. Call weekdays from 8:00 a.m. to 4:30 p.m.

The Information and Referral Line is for families, health care providers, public health nurses, teachers, social workers and anyone who needs help identifying and locating resources for children with special health needs. It offers a listing of services and resources provided by public and private agencies. Both national and state information is available.

We can provide you with information about:

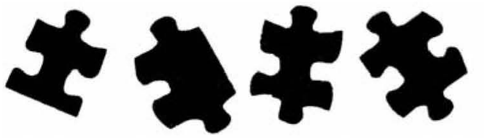
- educational services
- financial assistance resources
- home health care
- legal resources
- protection and advocacy
- service coordination
- specialized equipment
- summer camps
- support groups
- transportation

When You Call 651-215-8956 or 1-800-728-5420

A MCSHN information specialist will:

- Ask questions regarding the type of assistance you are seeking, the child's condition and where the child and/or family lives.

- Provide information about resources and services to meet your needs. Contact names, addresses and phone numbers will also be provided.



This project is funded in part through federal funding from Part C – Infants and Toddlers Program, IDEA. Upon request, this material can be made available in alternative formats, such as large print or audiotape. Printed on recycled paper.

Division of Family Health
85 East Seventh Place, Suite 400
P.O. Box 64882
St. Paul, MN 55164-0882
651-215-8956
1-800-728-5420

IC #141-1411 12/03 Rev.

Intentionally Left Blank

APPENDIX E – Minnesota Birth Defects Information System Opt-Out Form

Intentionally Left Blank

MINNESOTA MDH DEPARTMENT OF HEALTH

Birth Defects Opt-Out

Birth Defects Information System

Data privacy laws strictly protect the information in the Birth Defects Information System. The data is used to monitor the rates of birth defects in Minnesota. This helps discover if there are unusual patterns. Also, the data is useful for finding out how to prevent birth defects in the future.

Every measure is taken to keep this data secure and make it impossible to identify you or your child. However, you may choose to have the personal identifying information removed from the system.

Please fill out the form on the back of this sheet if you would like your personal identifying information removed.

If you have any questions, please call Myron Falken at (651) 201-4898.

Birth Defects Opt-Out Form

Birth Defects Information System

1. Please remove the personal identifying information as listed below.

2. **PRINT** the information below:

Name of Infant	Parent(s) Full Name
Birth Date	Street Address
	City/State/Zip

3. **SIGN** this form below.

By signing below, you acknowledge:

- I have received and read the Minnesota Department of Health's fact sheet concerning birth defects.
- I have been notified of Minnesota Statute 144.2215 concerning my right to have my child's and my personal identifying information removed from the birth defects database.
- I have been informed that more information on birth defects, including the statute, is available at: www.health.state.mn.us/divs/eh/birthdefects/index.html .
- I understand that by removing personal identifying information, the Minnesota Department of Health will not be able to inform me of information related to the prevention, treatment, or cause of a particular birth defect.

Signature	____/____/____ Date	Witness
Relationship to Infant		Witness (print name)

4. **MAIL** this form to:

Minnesota Department of Health
Attn: EH Birth Defects Program
Freeman Building – Pod C
P.O. Box 64975
St. Paul, MN 55164-0975

For more information about the Birth Defects Program please call:
(651) 201-4892; or 1 (800) 657-3908; or TTD (651) 201-5797.

Division of Environmental Health
Environmental Surveillance and Assessment Section
Environmental Impacts Analysis Unit

Printed on Recycled Paper
April 2006

If you require this document in another format, such as large print, Braille or cassette tape, call (651) 201-5000.

For office use only: ____________________

Original: Birth Defects Information System **Copy:** MCSHN

APPENDIX F – Number of Birth Defects from MN Birth Certificates

Intentionally Left Blank

Number of Birth Defects by Specific Defect from MN Birth Certificates, 1996-2004

	Number of Birth Defects								
	1996	**1997**	**1998**	**1999**	**2000**	**2001**	**2002**	**2003**	**2004**
Anencephalus	7	17	8	9	11	7	6	10	7
Spina Bifida	15	19	9	16	14	10	10	13	5
Hydrocephalus	29	19	16	24	10	12	12	21	7
Microcephalus	4	6	5	5	5	3	3	5	2
Central Nervous System	28	16	20	17	19	21	21	25	24
Heart Malformations	66	72	49	62	70	56	58	73	73
Circulatory/Respiratory	51	47	52	48	54	47	42	57	65
Rectal Atresia/Stenosis	7	3	4	4	9	2	6	5	5
Tracheo-Esophageal	14	15	13	11	21	7	9	5	7
Omphalocele/Gastroschisis	14	15	14	18	20	20	16	13	12
Gastrointestinal	31	39	20	34	21	16	24	21	24
Malformed Genitalia	40	27	23	21	29	24	26	24	23
Renal Agenesis	9	9	6	4	7	11	6	15	9
Urogenital	134	115	101	93	93	88	74	97	93
Cleft-Lip/Palate	61	68	61	56	60	63	66	45	53
Polydactyly	54	35	40	37	44	32	26	27	37
Club Foot	44	44	27	34	43	39	44	36	51
Diaphragmatic Hernia	17	9	9	10	9	6	7	8	6
Musculoskeletal	115	86	97	112	100	80	74	65	73
Down Syndrome	27	26	34	34	30	33	28	29	40
Chromosome	33	36	26	52	41	20	27	26	26
Other	302	283	249	231	252	234	269	258	237
Total Number of Defects	1,102	1,006	883	932	962	831	854	878	879
Total Births	63,682	64,491	65,207	65,953	67,451	66,617	68,178	70,191	70,728

Intentionally Left Blank

APPENDIX G – Rates of Birth Defects from Minnesota Birth Certificates

Intentionally Left Blank

Birth Defect Rates* (per 10,000) from Birth Certificates 2000 - 2004

Birth Defect	Nationwide Birth Certificates 2000	Minnesota Birth Certificates				
		2000	2001	2002	2003	2004
Anencephalus[1]	1.05	1.63	1.05	.88	1.4	1.0
Spina Bifida	2.04	2.08	1.50	1.47	1.9	0.7
Hydrocephalus	2.33	1.48	1.80	1.76	3.0	1.0
Microcephalus	0.70	0.74	.45	.44	0.7	0.3
Central Nervous System	2.04	2.82	3.15	3.08	3.6	3.4
Heart Malformations	12.30	10.38	8.41	8.51	10.4	10.3
Circulatory/Respiratory	13.60	8.01	7.06	6.16	8.1	9.2
Rectal Atresia/Stenosis	0.83	1.33	.30	.88	0.7	0.7
Tracheo-Esophageal	1.19	3.11	1.05	1.32	0.7	1.0
Omphalocele/Gastroschisis	2.93	2.97	3.00	2.35	1.9	1.7
Gastrointestinal[2]	2.94	3.11	2.40	3.52	3.0	3.4
Malformed Genitalia[3]	8.29	4.30	3.60	3.82	3.4	3.3
Renal Agenesis	1.36	1.04	1.65	.88	2.1	1.3
Urogenital[4]	9.78	13.79	13.21	10.85	13.8	13.2
Cleft-Lip/Palate	8.08	8.90	9.46	9.68	6.4	7.5
Polydactyly	8.58	6.52	4.80	3.81	3.8	5.2
Club Foot	5.63	6.37	5.84	6.45	5.1	7.2
Diaphragmatic Hernia	1.06	1.33	.90	1.03	1.1	0.8
Musculoskeletal[5]	21.37	14.83	12.01	10.85	9.3	10.3
Down Syndrome	4.62	4.45	4.95	4.11	4.1	5.7
Chromosome[6]	3.91	6.08	3.00	3.96	3.7	3.7
Other[7]		37.36	35.13	39.46	36.8	33.5

* *Birth defect reporting on birth certificates is known to greatly underestimate the actual number of birth defects. Rates of birth defects based on birth certificate data should be used with extreme caution. The rates listed on this table are useful for comparing Minnesota's reporting with national reporting from birth certificates, but they are not necessarily representative of the true rate of birth defects in Minnesota.*

1=Encephalocele
2=Hirshsprung's Disease
3=Hypospadias and Epispadias
4=Obstructive Genitourinary Defect
5=Reduction Deformity, Upper Limbs; Congenital Hip Dislocation
6=Trisomy 13 and 18
7=Anophthalmia, Congenital Cataract, Anidridia, Anotia Microtia, Choanal Atresia, Fetal Alcohol Syndrome

Intentionally Left Blank

APPENDIX H – Birth Defects Validation Study Form

Intentionally Left Blank

MINNESOTA MDH DEPARTMENT OF HEALTH

Birth Defects
Validation Study Form 2006

Abstractors Name ___________________________________

Reviewer's Name ___________________________________

Date ____________________

Medical Record/Case _______________________

Circle discrepancy for each variable

Variable Name	Major Discrepancy	Minor Discrepancy
Infant First Name	Incorrect Spelling	
Infant Middle Name		Incorrect Spelling
Infant Last Name	Incorrect Spelling	
Infant Suffix		Missing
Infant Date of Birth	Incorrect/Not Found	
Mother's First Name	Incorrect Spelling	
Mother's Middle Name		Incorrect Spelling
Mother's Last Name	Incorrect Spelling	
Mother Suffix		Incorrect/Not Found
Also Known As		Not Required
Mother's Address	Not Found	Incorrect
Mother's County	Not Found/Incorrect	
Mother's City	Not Found	Incorrect
Mother's State	Not Found/Incorrect	

Mother’s Zipcode		Incorrect/Not Found
Mother’s Date of Birth	Incorrect Month or Year	Incorrect Day
Mother’s Telephone Number		Not Found/Incorrect
Father’s Last Name		Not Found/Incorrect
Father’s First Name		Not Found/Incorrect
Father’s Middle Name		Not Found/Incorrect
Father’s Birth Date		Not Found/Incorrect
Father’s Telephone		Not Required
Adoptive/Foster Care		Incorrect/Not Found
CLW Relationship		Not Found/Incorrect
CLW County		Not Found/Incorrect
CLW Last Name		Not Found/Incorrect
CLW First Name		Not Found/Incorrect
CLW Middle Name		Not Found/Incorrect
CLW Address		Not Found/Incorrect
CLW County		Not Found/Incorrect
CLW City		Not Found/Incorrect
CLW State		Not Found/Incorrect
CLW Zipcode		Incorrect/Not Found
CLW Telephone		Not Found/Incorrect
Address of Guardian	Incorrect County or City	Incorrect Residence
Birthing Hospital	Incorrect Facility	Incorrect Spelling
Birth Weight	Incorrect Weight or Not Listed	

Head Circumference	Incorrect/Not Found	
Gender	Incorrect Gender or Not Listed	
Hospital Transferred To		Not Found
Apgar Score	Incorrect/Not Found	
Admission/Discharge	Incorrect Dates	Not Found
Plurality	Not Found	Incorrect
Co-Twins LB/SB	Not Found	Incorrect
Did Infant Die	Not Found	
Ethnicity		Incorrect/Not Found
Race		Incorrect/Not Found
Case Finding Number		Incorrect
Medical Record #		Incorrect
Facility Name		Incorrect
Did Mom Receive Prenatal Care		Incorrect/Not Found
Pregnancy Record		Incorrect/Not Found
Family History of BD	Not Found	
LMP	Not Found/Incorrect Month Year	Incorrect Day
Ultra Sound	Not Found/Incorrect Month Year	Incorrect Day
Clinical Exam	Not Found/Incorrect Month Year	Incorrect Day
Prenatal Proc & Tests	Not Found/Incorrect Month Year Incorrect Results of Diagnosis	Incorrect Day
ICD-9 Coding	Incorrect First 3 Digits	Incorrect Last 2 Digits
Diagnosis Date	Incorrect Month Year/Not Found	
Verbatim	Incorrect/Not Found	

Intentionally Left Blank

APPENDIX I – Abstractor Records-Tracking Spreadsheet

Intentionally Left Blank

Abstraction Tracking

- Medical Record Number
- Patient Name
- Child’s Date of Birth
- Facility
- Case Finding Source
- ICD-9 Codes/Potential Birth Defect
- Date MR was last requested
- Status of Abstract
- Comments
- Date Abstracted
- Date Referred to MCSHN

Intentionally Left Blank