Birth Defects Program

2008 Annual Report

MINNESOTA
MDH
DEPARTMENT OF HEALTH

Environmental Impacts Analysis Unit

June 2009

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MINNESOTA MDH DEPARTMENT OF HEALTH

Environmental Health Division
Environmental Surveillance and Assessment Section
Environmental Impacts Analysis Unit – Birth Defects
P.O. Box 64975
St. Paul, Minnesota 55164-0975

Summary

Effective March 2005 State of Minnesota statutory language (MS144.2215-2219) authorized the Minnesota Department of Health (MDH) to collect information on birth defects in Minnesota. The MDH Birth Defects Program gathers data about babies born each year with certain health conditions diagnosed within the first year of life. The mission of the Birth Defects 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 health care providers and the public regarding birth defects, and
- Stimulate research on risk factors, treatment, prevention, and the cure of birth defects.

The Birth Defects Program began active surveillance on June 1, 2005. The data collected by the abstractors is reviewed and entered into the Birth Defects Information System (BDIS) database. The BDIS is built to gather high quality data, ensure connection to services, and support primary prevention efforts. Children are either notified by mail of services available to them through a pamphlet developed by the Minnesota Children with Special Health Needs (MCSHN) program, or notices are sent to local public health agencies to help ensure families are connected to local and state resources. To date, the system has been successfully implemented in Hennepin and Ramsey counties.

This report includes: an overview and evaluation of the active surveillance procedures used for BDIS; counts and estimated prevalence rates for selected birth defects for children born in Minnesota in 2006 and 2007; the number of children referred for services; and a summary of recent primary prevention efforts, which focus on folic acid education and outreach.

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Introduction

Effective March of 2005 State of Minnesota statutory language (MS144.2215-2219) authorized the Minnesota Department of Health (MDH) to collect information on birth defects in Minnesota. The MDH Birth Defects Program gathers data about babies born each year with certain health conditions diagnosed within the first year of life. The mission of the Birth Defects Program is to help children thrive, grow, and be as healthy as possible. The statute required the following: "The commissioner of health shall design a system that allows the commissioner to:

- monitor incidence trends of birth defects to detect potential public health problems, predict risks, and assist in responding to birth defects clusters;
- more accurately target intervention, prevention, and services for communities, patients, and their families;
- inform health professionals and citizens of the prevalence of and risks for birth defects;
- conduct scientific investigation and surveys of the causes, mortality, methods of treatment, prevention, and cure for birth defects;
- modify, as necessary, the birth defects information system through demonstration projects;
- remove identifying information about a child whose parent or legal guardian has chosen not to participate in the system as permitted by section 144.2216, subdivision 4;
- protect the individually identifiable information as required by section 144.2217;
- limit the dissemination of identifying information as required by sections 144.2218 and 144.2219; and
- use the birth defects coding scheme defined by the Centers for Disease Control and Prevention (CDC) of the United States Public Health Service."

The statute did not include financial support for Birth Defects (BD) Program activities. Therefore, MDH's BD Program is primarily funded at this time by grants from the Centers for Disease Control and Prevention (CDC) and through a small amount of State General Fund support. The BD Program has also received in-kind contributions through collaborations with the following MDH programs:

- Fetal Alcohol Syndrome (FAS)
- Genomics Program
- Maternal and Child Health (MCH)
- Minnesota Children with Special Health Needs (MCSHN)
- Office of Minority and Multicultural Health (OMMH)

As well as the following Non-MDH collaborators:

- Birth Defects Work Group (an advisory work group)
- Specialty Physicians (for coding purposes)
- Minnesota Folic Acid Council (FAC)

- Gillette Children's Specialty Healthcare
- Iowa Birth Defects Registry
- Local Public Health
- March of Dimes (MOD)
- Mayo Clinic of Rochester
- National Birth Defects Prevention Network (NBDPN)
- Shriners Hospitals for Children/Twin Cities
- University of Minnesota

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

Data Collection

The MDH BD Program began active surveillance on June 1, 2005. To date, the BD Program has gained access to records in a total of 15 locations (Table 1). These facilities represent all birthing hospitals in Hennepin and Ramsey counties, with an estimated capture of approximately 50 % of all births in Minnesota. As funding becomes available, the BD Program plans to expand abstraction to all hospital Neonatal Intensive Care Units (NICUs) and birthing hospitals statewide.

Table 1: Facilities providing information for case finding as of 1/1/2008

HOSPITAL COUNTY	HOSPITAL NAME
HENNEPIN	Abbott Northwestern Hospital Children’s Hospitals and Clinics Fairview Southdale Hospital Fairview-University Medical Center Hennepin County Medical Center KDWB Pediatric Physicians Methodist Hospital HealthSystem Minnesota North Memorial Medical Center
OLMSTED	Mayo Clinics, Rochester
RAMSEY	Health East-St. John’s NE Community Hospital Regions Hospital St. Joseph’s Hospital St. Paul Children’s Hospital United Hospital
WASHINGTON	HealthEast-Woodwinds Health Campus

Participating hospitals regularly notify the BD Program of children discharged from their hospital with a potential birth defect. The potential cases are appended to a tracking table to check for any previous abstraction for the same child and defect. If the case is new or a new defect is noted, the medical record at the reporting hospital is reviewed by one of two full-time abstractors. Both abstractors have access to all Hennepin and Ramsey county facilities. However, abstractors have been assigned specific hospitals to maintain a consistent point of contact and ensure a collaborative, working relationship.

The BD Program uses the Minnesota Birth Defects Coding List (Appendix A). Birth conditions include 44 of the birth defects used in the National Birth Defects Prevention Study (NBDPS) and a single ventricle defect. The list used by the NBDPS was developed collaboratively by the CDC and the NBDPN; the single ventricle defect was included at the recommendation of a collaborating physician.

Confirmed cases are entered into a database on a laptop computer. At the completion of each abstraction an error checking program is run to identify missing or improper field entries. Completed abstractions are downloaded weekly to the main database where they are matched to any previous abstractions and assigned a unique identification number. The downloaded records are then reviewed, validated, and final codes are assigned to each case. The laptops are secured by both password and encryption and the database resides on an MDH server secured by a firewall and controlled access to network drives.

As of January 1, 2009, 3,276 cases were validated and entered into BDIS, which includes children born in 2005 through 2008. Because children may have additional birth defects diagnosed up to their first birthday, these 3,276 cases incurred 3,366 unique abstractions and identified a total of 5,391 unique birth defects. Figure 1 shows the percentage of cases with one or multiple birth defects by all children in the database (n = 3,276) and by only those children who opted out of the system by having their identifying information removed from the database (n = 137). About 38 % of cases in BDIS have more than one birth defect.

Figure 1: Number of birth defects per case among cases born between 2005 and 2008; abstracted by 1/1/2009.

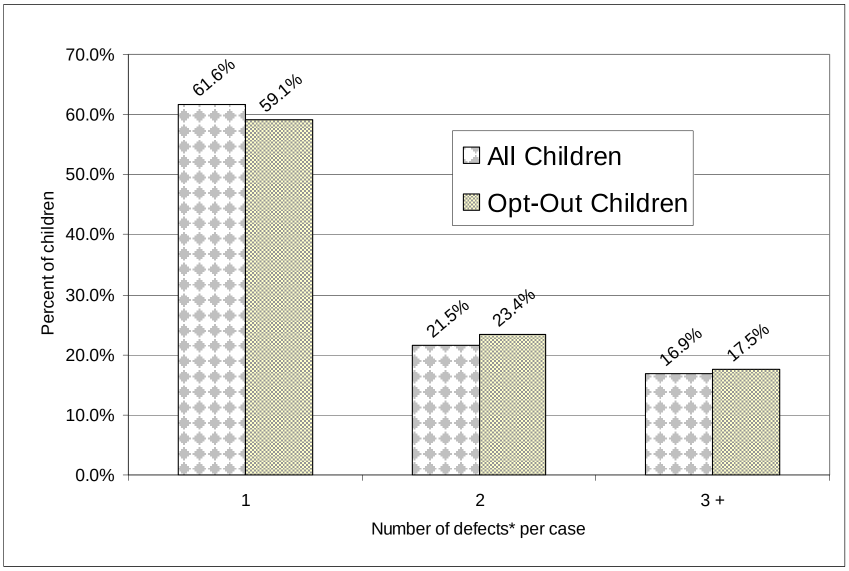


Figure 2 shows the breakdown of unique birth defects by groups of defect and by all children in the data base (n = 3,276) and by those who opted out (n = 137). The majority of validated birth defects identified in all children were cardiovascular (48 %), followed by genitourinary (18 %) and gastrointestinal (12 %) defects. Although the number of opt-out cases was significantly lower, the distribution of defects for the opt-out population was virtually the same as for the "all children" population. Therefore, it does not appear that the type of birth defect was associated with the rate a family opted out of BDIS.

Figure 2: Number of birth defects by defect group among cases born between 2005 and 2008; abstracted by 1/1/2009.

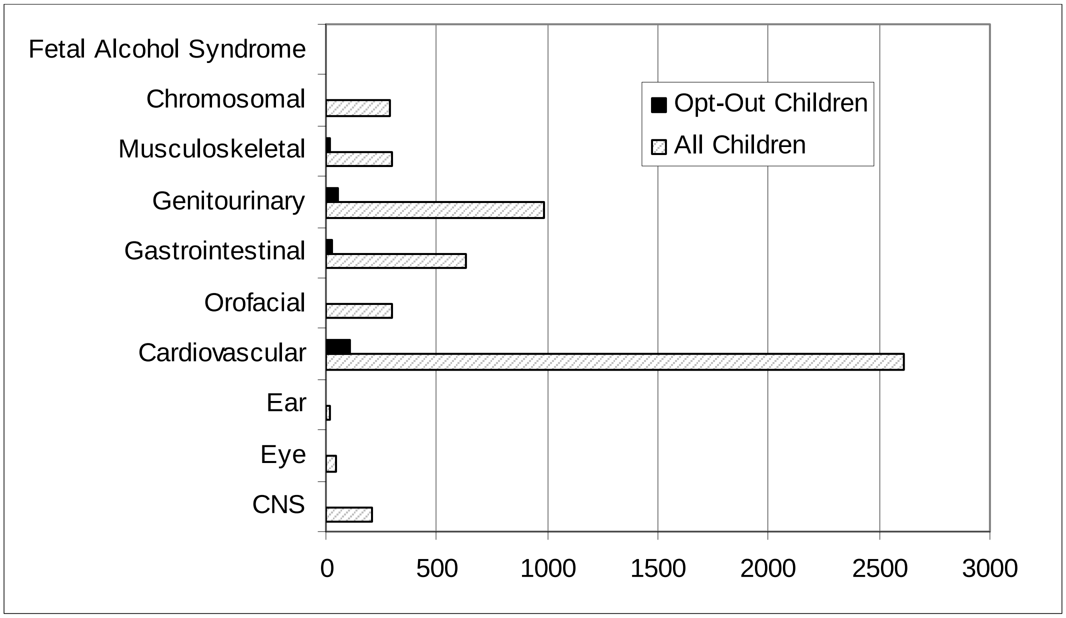


Table 2 below lists the rates per 10,000 live births for 45 selected birth defects from 2006-2007. The data include children whose mothers were residents of Hennepin and Ramsey counties at the time of birth. Because the rates include only two years of data, the rates may vary considerably compared with data from other states that have been collecting birth defects information for a longer time period. Rates may vary depending upon the type of surveillance system that each state uses to collect data. In Minnesota an active surveillance system is used to collect data from hospitals in Hennepin and Ramsey counties. Another type of surveillance used by some states is passive surveillance, which relies on hospital reporting and may have bias due to under or over reporting. This is the first time that birth defect rates are reported for Minnesota based on active surveillance data.

Table 2: Birth Defects counts* and prevalence rates for Hennepin and Ramsey counties; 2006 – 2007 data. Rates (in parenthesis) are per 10,000 live births.

Defect	Race/Ethnicity						
	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Other/ Unknown	Total
Central Nervous System							
Anencephalus	<5 (<1.94)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	3 (0.62)
Spina bifida without anencephalus	16 (6.2)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	24 (4.92)
Hydrocephalus without spina bifida	8 (3.10)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	12) (2.46
Encephalocele	<5 (<1.94)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	4 (0.82)
Microcephalus	9 (3.49)	8 (9.11)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	25 (5.13)
Eye							
Anophthalmia/microphthalmia	7 (2.71)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	13 (2.67)
Congenital cataract	6 (2.33)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	11 (2.26)
Aniridia	<5 (<1.94)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	1 (0.21)
Ear							
Anotia/microtia	9 (3.49)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	13 (2.67)
Cardiovascular							
Common truncus	<5 (<1.94)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	5 (1.03)
Transposition of great arteries	17 (6.59)	6 (6.84)	<5 (<7.67)	9 (16.32)	<5 (<82.9)	<5 (<32.1)	35 (7.18)
Tetralogy of Fallot	19 (7.36)	11 (15.5)	<5 (<7.67)	6 (10.88)	<5 (<82.9)	<5 (<32.1)	38 (7.79)
Single ventricle	<5 (<1.94)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	7 (1.44)
Ventricular septal defect	122 (47.3)	56 (63.8)	47 (72.1)	17 (30.8)	<5 (<82.9)	<5 (<32.1)	248 (50.9)
Atrial septal defect	183 (70.9)	79 (90.0)	66 (101.3)	27 (49.0)	5 (82.9)	<5 (<32.1)	364 (74.6)
Endocardial cushion defect	18 (6.98)	5 (5.7)	<5 (<7.67)	5 (9.06)	<5 (<82.9)	<5 (<32.1)	31 (6.36)
Pulmonary valve atresia and stenosis	18 (6.98)	7 (7.97)	7 (10.74)	7 (12.69)	<5 (<82.9)	<5 (<32.1)	41 (8.41)
Tricuspid valve atresia and stenosis	<5 (<1.94)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	4 (0.82)
Ebstein’s anomaly	<5 (<1.94)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	2 (0.41)
Aortic valve stenosis	<5 (<1.94)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	3 (0.62)
Hypoplastic left heart syndrome	12 (4.65)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	16 (3.28)
Patent ductus arteriosus	63 (24.4)	35 (39.9)	23 (35.3)	10 (18.13)	<5 (<82.9)	<5 (<32.1)	134 (27.5)
Coarctation of aorta	24 (9.30)	7 (7.97)	5 (7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	39 (8.00)

Orofacial							
Cleft palate without cleft lip	27 (10.5)	6 (6.84)	6 (9.21)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	44 (9.02)
Cleft lip with and without cleft palate	36 (14.0)	13 (14.8)	9 (13.8)	7 (12.7)	<5 (<82.9)	<5 (<32.1)	66 (13.5)
Choanal atresia	<5 (<1.94)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	8 (1.64)
Gastrointestinal							
Esophageal atresia/tracheoesophageal fistula	12 (4.65)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	16 (3.28)
Rectal and large intestinal atresia/stenosis	14 (5.43)	8 (9.11)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	25 (5.13)
Pyloric stenosis	86 (33.3)	20 (22.78)	17 (26.1)	<5 (<9.06)	5 (82.92)	<5 (<32.1)	134 (27.47)
Hirshsprung's disease (congenital megacolon)	6 (2.33)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	8 (1.64)
Biliary atresia	<5 (<1.94)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	3 (0.62)
Genitourinary							
Renal agenesis/hypoplasia	13 (5.04)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	22 (4.51)
Bladder exstrophy	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Obstructive genitourinary defect	98 (38.0)	31 (35.3)	25 (38.4)	15 (27.2)	<5 (<82.9)	<5 (<32.1)	171 (35.1)
Hypospadias and Epispadias	96) (37.2)	32 (36.5)	14 (21.5)	7 (12.7)	<5 (<82.9)	<5 (<32.1)	151 (31.0)
Musculoskeletal							
Reduction deformity, upper limbs	<5 (<1.94)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	11 (2.26)
Reduction deformity, lower limbs	<5 (<1.94)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	9 (1.85)
Gastroschisis	14 (5.43)	6 (6.84)	<5 (<7.67)	7 (12.7)	<5 (<82.9)	<5 (<32.1)	33 (6.77)
Omphalocele	5 (1.94)	5 (5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	12 (2.46)
Congenital hip dislocation	15 (5.81)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	26 (5.33)
Diaphragmatic hernia	9 (3.49)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	12 (2.46)
Chromosomal							
Trisomy 13	<5 (<1.94)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	7 (1.44)
Down Syndrome	60 (23.3)	25 (28.5)	14 (21.5)	5 (9.06)	<5 (<82.9)	<5 (<32.1)	106 (21.7)
Trisomy 18	8 (3.10)	<5 (<5.70)	<5 (<7.67)	<5 (<9.06)	<5 (<82.9)	<5 (<32.1)	9 (1.85)
Other							
Fetal Alcohol Syndrome	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Total Defects	**1,055**	**404**	**286**	**156**	**22**	**23**	**1,946**

*Numbers of birth defects that are less than 5 are not shown for individual race or ethnicity categories to preserve data privacy.

After entry into BDIS, the parents of each validated birth defect case is sent a letter (Appendix B) with information on the BD Program. The letter also 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). If parents do not want their child’s identifying information included in the BDIS database the completed Birth Defects Opt-Out Form is returned to the BD Program. Upon receipt of a completed Opt-Out Form, the BD

Program removes an individual's personal identifying information from BDIS and sends the family a letter confirming this action. As of January 1, 2009, 137 parents or guardians (4.2%) have returned an opt-out form to MDH requesting that all identifying information pertaining to them and their child be removed from BDIS. A chart showing the data flow and management in BDIS, from abstraction through referral/notification, data quality checks and data analysis, is presented in Appendix F.

In addition to being entered into BDIS, all FAS data collected by the abstractors are validated using the CDC software "FASSLink" (Fetal Alcohol Syndrome Surveillance Link) to meet FAS Program grant objectives. As of January 1, 2009 there were 236 cases abstracted, resulting in 44 confirmed cases of FAS using the FASSLink software. No rates are available, because the BD Program continues to examine data regarding the county of residence for the mothers of the identified cases. The data assessment process is complicated by the fact that more than 70 % of FAS children do not live with their biological parent.

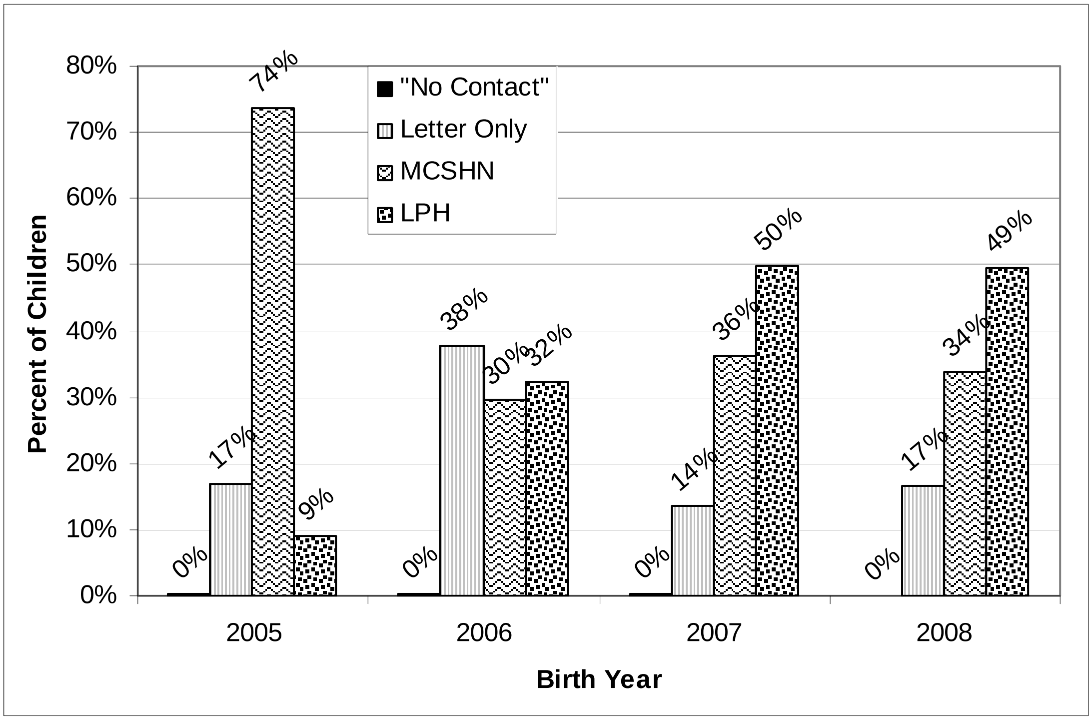
Notification/Referral to Services

MCSHN is the MDH program accountable for the performance of core public health functions for children with special health needs. Therefore, all validated cases receive information about MCSHN from the BD Program (see Appendices B and D). The goal is to ensure appropriate public health resources are provided to the affected families. Families contacting MCSHN receive advice on available/appropriate public health services and referrals to agencies and programs.

Local public health agencies serving each of Minnesota's 87 counties provide most of the case management and direct services for birth defects in Minnesota. These agencies are encouraged to participate within the limits of their resources. As of January 1, 2009 local public health agencies serving 53 counties have received notification of children with select birth defects in their counties. During 2009, staff from the BD Program will meet with the counties who are not currently receiving notices of cases entered into the BDIS to encourage their participation.

Figure 3 documents trends in the follow-up of cases born between 2005 and 2008 and abstracted as of January 1, 2009. The data show an increasing participation of local public health agencies over time. The number of children working with MCSHN annually has remained relatively constant. About one in five families do not receive a personal contact from either MCSHN or the local public health agency (e.g. "letter only"). Lack of contact is possible due to families moving out of state, changing phone numbers, opt-outs, and repeated attempts at reaching them being unsuccessful. However, all families are sent an informational packet listing available resources and referrals. MDH will continue to make every effort to ensure that all families are contacted in a timely manner whenever possible.

Figure 3: Case follow-up patterns among cases born between 2005 and 2008; Abstracted by 1/1/2009. Bars represent the method of contacting the family. Values less than 0.5 % are reported as zero.



Timeliness of Abstraction and Referrals

The abstraction and referral process, as shown in Appendix F, is started by a secure electronic notice of potential cases to MDH by the reporting facilities. Previous abstractions of an individual are checked to avoid duplication of effort. MDH monitors information on dates, hospitals, and other medical record information for each case. The average times between birth, abstraction activities, and notification or referral are used by MDH to ensure that all medical records are reviewed and completely abstracted. This evaluation data allows the BD Program to build upon areas of strength and understand sources of delay in providing referral to services for affected families.

Average times between events for BDIS cases born between 2005 and 2008 are reported in Table 3. The time between a child's date of birth and date of medical record request by MDH abstractors is an estimate of the average time before MDH is made aware by the hospitals of a child with a potential birth defect. The average child in BDIS born in 2005, 2006 and 2007 was over about 3 months old before MDH requested their medical record. Since the start of Minnesota's Birth Defects Program, several of the participating hospitals have switched from paper to electronic medical records. The use of electronic records, and the more streamlined notification process that comes with experience, has shortened the time it takes for MDH to become aware of potential cases at participating hospitals.

The time between the date of abstraction of a child's medical record and the date the Birth Defects Program sends the affected family a letter with information about the system and services available is an estimate of the average turn-around time for MDH to process each case. This time has remained steady over the most recent two years of operation, at just under a month. Overall, the time from the birth of a case to the time affected families received a parent information packet/letter from the Birth Defects program about available services was over 6 months (27.2 weeks) for cases born in 2005, and had been reduced to under 4 months (15.2 weeks) by 2008.

Table 3: Average time between events completed by the Birth Defects program; Among cases reviewed by 1/1/2009 (less cases abstracted by Mayo Hospitals and Clinics)

	Birth to Hospital Discharge		Hospital Discharge to Abstraction		Abstraction to Letter* sent	
Abstraction year	N	Weeks	N	Weeks	N	Weeks
2005	461	9.1	461	13.4	445	4.7
2006	947	7.3	947	11.4	918	4.0
2007	897	6.2	897	9.8	882	3.6
2008	641	4.0	641	7.7	635	3.5

*Letter = Parent information packet containing letter, fact sheet, MCSHN brochure, MA guidelines, and opt out form

Completeness of Case Finding

Case finding is an important aspect of any surveillance system. Therefore, the use of multiple data sources is important to help ensure data completeness and that all cases are identified. In addition to medical records, the Birth Defects Program uses the following sources for case finding:

- Birth Certificates
- Hospital Discharge Summaries
- Medical Records
- Medicaid Data

Many studies have shown that birth defects are severely under-reported on birth certificates. Because birth certificates are not a very accurate source for birth defect data, high confidence should not be placed in them as a data source. However, birth certificates can be matched to BDIS records to determine completeness of our active surveillance system and will be used in other data quality steps.

The Minnesota Hospital Discharge Database (MnHDD) for years 2005 and 2006 was evaluated as a passive data source for case finding. The MnHDD was searched for all occurrences of an ICD-9 code corresponding to a birth defect and analyzed to identify possible duplicates in the de-identified data. Because the MnHDD data are not identified, duplicates result from a child being seen multiple times. A new discharge record is generated for each visit. The MnHDD is not useful for case finding but will be used to determine how many cases are seen in facilities outside of the Minneapolis-St. Paul metropolitan area. However, MnHDD data will be useful when determining the patterns for birth defects seen at specific hospitals and also to determine which hospitals are priorities for case finding and abstraction. Although the information is complete, MnHDD data cannot be used for patient referrals because the data are de-identified and greater than one year old. While birth certificates and Medicaid data were used for case finding for 2007 and 2008, both sources provide a limited amount of data on new cases. All new cases identified were abstracted and included in the BDIS if they were a confirmed case.

Data Accuracy

During 2006, the BD Program switched from paper to laptop data collection by the abstractors. To check for data accuracy, a random sample of selected medical records was examined in 2008. Of the 500 records abstracted on paper from 2007 – 2008, five percent (26) were randomly selected and re-abstracted. A review of the re-abstracted charts indicated that overall the data collection is of high quality. The following items were identified through the re-abstraction process; number in parenthesis indicates frequency of occurrence:

- Differences in recorded birth weight (3);
- Differences in race (3);
- Missing mother's age (1);
- Missing parental information (1);
- Differences in gestational age (5);
- Missing postnatal procedure (1);
- Minor differences in coding (5).

The abstractors and epidemiologist met to discuss ways that may help identify and eliminate errors in routine operations. Additional policies and procedures in both abstraction methods and BDIS operation were developed to help eliminate future errors in data collection. Data quality is ensured by regular checks on abstractions, routine staff meetings, logic checks incorporated into BDIS programming, and close attention to established policies and procedures.

Data Cleaning and Retention

The BDIS database, a relational database consisting of multiple tables, is routinely cleaned using a multi-step process on a duplicate of the database. Each table within the database is compared to the main table to identify any unmatched records. Matched records in each table are checked for appropriate and logical entries. Finally, logical checks between the tables are made to ensure all necessary entries are included in the database. In addition to periodic cleaning of tables within the database, BD Program staff has developed a retention schedule for all of the BDIS records. The retention schedule helps ensure that records are maintained for quality control efforts, for answering questions that may arise as part of the notification/referral process, and for ensuring that all data are handled consistent with all applicable MDH policies and the Minnesota Data Practices Act. The retention schedule was revised in 2008 to more accurately reflect current procedures (which are regularly reviewed and updated based on program evaluation).

Folic Acid Prevention Activities

The BD Program continues to work with the Minnesota Folic Acid Council (FAC) to recruit collaborating partners and pursue educational opportunities.

During 2007, Minnesota's "Folic Acid Guidelines for the Prevention of Neural Tube Defects (NTDs)" were developed. The MDH Birth Defects Program worked collaboratively with a large group of physicians and public health experts to create guidelines for physicians to use as a tool in determining the correct dose of folic acid. The guidelines discuss special considerations that need to be taken into account when determining the correct amount of folic acid a woman needs daily, based on physician advice. A reference manual with supporting documentation was also created. The Minnesota Medical Association (MMA) has supported and endorsed these guidelines for all Minnesota women. The guidelines can be found in Appendix G and at: http://www.health.state.mn.us/divs/eh/birthdefects/reports/faguidelines.pdf .

In addition to the guidelines, folic acid promotional materials (Figure 4) were developed by MDH and distributed to the organizations collaborating on the distribution of the NTD guidelines. Materials from the March of Dimes were also used. Figure 4 shows the promotional material used in support of folic acid education.

Figure 4: Folic Acid promotional materials

In addition to protecting the general population, MDH is committed to reaching out to communities with health disparities. Therefore, education and outreach efforts using the materials in Figure 4 were targeted to Hispanic women, who have been shown to have significantly higher rates of neural tube defects in their newborns. The folic acid education and outreach effort during 2008 included highlighting NTD as a topic on the MDH birth defects web site (www.health.state.mn.us/birthdefects), providing copies of the guidelines to the Maternal and Child Health program at the University of Minnesota (UM MCH), the March of Dimes Minnesota Chapter Board of Directors, CLEARCorps USA, a local advocacy organization, and several health care systems (e.g. Blue Cross/Blue Shield, Regions Hospital, Gillette Children's Specialty Healthcare clinics). The UM MCH program posted the guidelines on their listserv, which reaches health providers throughout the country.

In 2007 the BD Program contracted with the Emergency and Community Health Outreach (ECHO) organization to produce seven 20-minute television segments on the benefits of using folic acid to prevent birth defects. Each segment was developed in different languages, including: Cambodian, English, Hmong, Lao, Somali, Spanish and Vietnamese. The show was broadcast during January 2008, and continues to be available on the ECHO Web site and via DVD format from MDH. One hundred twenty six copies of the DVD have been distributed to a variety of partners, including local public health, hospitals, clinics, physicians, health plans, and individuals.

The MDH Pregnancy Risk Assessment Monitoring System (PRAMS) is part of a CDC initiative to reduce infant mortality and low birth weight. PRAMS is an ongoing, state-level, population-based surveillance system that identifies and monitors selected maternal experiences and behaviors before, during, and after pregnancy. Each state uses the same standardized mail/telephone method to survey mothers who recently gave birth. Responses are then weighted to be representative of all women who gave birth in each state during that year.

As shown in Table 4, among Minnesota mothers who had a live birth in 2006, 35.3% (95% CI: 32.9-37.7) reported taking a multivitamin every day of the week during the month before becoming pregnant. There has been no significant change in reported pre-pregnancy multivitamin use since Minnesota PRAMS began in May 2002. Mothers who are younger, Hispanic, unmarried, have less education, or lower income are less likely to have reported using pre-pregnancy vitamin daily. Table 4 also includes a data breakdown by age, race, ethnicity, education, marital status, prior live births, infant's birth weight, maternal residence, income, WIC recipient, and mother on public insurance. The data in Table 4 was provided to the BD Program by the MDH Community and Family Health Division.

Starting with 2009 births, the Minnesota PRAMS will begin using the Phase 6 PRAMS questionnaire, which contains a re-worded question about pre-pregnancy vitamin use that now specifically mentions folic acid. There also are several questions related to preconception health.

Table 4: 2006 MDH Pregnancy Risk Assessment Monitoring System Survey Results for Minnesota

MATERNAL NUTRITION QUESTION: VITAMIN USE AND FOLIC ACID

"During the month before you got pregnant with your new baby, how many times a week did you take a multivitamin or a prenatal vitamin? These are pills that contain many different vitamins and minerals."

Demographic Groups	Total Respond.#	DIDNT TAKE VITAMIN			1-3 TIMES/WEEK			4-6 TIMES/WEEK			EVERY DAY/WEEK		
		N	%	C.I.(95%)	N	%	C.I.(95%)	N	%	C.I.(95%)	N	%	C.I.(95%)
Total	**1553**	721	**48.5**	46.0-51.0	149	**9.5**	8.1-11.1	112	**6.8**	5.7- 8.1	571	**35.3**	32.9-37.7
Age													
< 20 years	83	60	73.1	62.5-81.5	6	6.9	3.1-14.7	1	1.4	0.2- 9.1	16	18.6	11.7-28.4
20-24 years	318	240	75.7	70.6-80.1	20	6.5	4.2- 9.9	7	2.1	1.0- 4.3	51	15.8	12.2-20.3
25-34 years	910	354	40.5	37.3-43.8	98	10.8	8.9-13.0	81	8.4	6.8-10.3	377	40.3	37.2-43.6
35+ years	242	67	29.9	24.2-36.2	25	10.1	6.9-14.7	23	9.7	6.5-14.2	127	50.3	43.9-56.7
Race													
White	1293	572	45.9	43.2-48.7	127	9.8	8.3-11.5	102	7.6	6.3- 9.2	492	36.7	34.1-39.3
Black	72	41	57.7	46.2-68.4	4	5.3	2.0-13.2	3	4.0	1.3-11.5	24	33.0	23.2-44.5

Other	180	106	60.4	52.9-67.4	18	10.3	6.6-16.0	6	3.0	1.3- 6.7	50	26.2	20.3-33.2
Hispanic origin													
Yes	101	70	69.9	60.1-78.1	8	8.1	4.1-15.6	3	3.0	1.0- 9.2	20	19.0	12.4-27.8
No	1425	639	46.7	44.0-49.3	140	9.7	8.3-11.4	108	7.2	6.0- 8.6	538	36.4	34.0-39.0
Education													
< High School	132	92	71.1	62.7-78.2	15	10.8	6.5-17.3	1	0.6	0.1- 4.0	24	17.6	11.9-25.1
High School	356	233	64.7	59.5-69.5	26	7.7	5.3-11.0	14	3.9	2.3- 6.5	83	23.8	19.6-28.5
Some College	416	201	49.0	44.2-53.8	44	10.6	8.0-14.0	32	7.8	5.5-10.8	139	32.6	28.3-37.3
College or more	628	182	29.2	25.8-32.9	64	10.1	8.0-12.7	64	10.1	8.0-12.7	318	50.5	46.7-54.4
Marital Status													
Married	1114	411	38.0	35.1-40.9	112	10.1	8.5-12.1	97	8.4	6.9-10.1	494	43.6	40.7-46.5
Other	439	310	70.9	66.4-74.9	37	8.2	6.0-11.1	15	3.4	2.1- 5.6	77	17.5	14.2-21.4
Prior live births													
None	651	296	47.2	43.4-51.1	52	7.9	6.1-10.3	44	6.3	4.7- 8.4	259	38.6	34.9-42.4
1 or more	901	425	49.4	46.1-52.7	97	10.6	8.7-12.8	68	7.1	5.6- 8.9	311	32.9	29.9-36.1
Infant's birth weight													
Under 2500 grams	91	47	53.1	42.7-63.2	3	3.6	1.2-10.5	6	6.2	2.8-13.3	35	37.1	27.8-47.5
2500+ grams	1462	674	48.2	45.6-50.8	146	9.9	8.4-11.5	106	6.8	5.7- 8.2	536	35.1	32.7-37.6

Maternal Residence												
7-County Metro	755	383	52.6	49.1-56.2	74	9.7	7.7-12.0	59	7.4	5.8- 9.5	239	30.3	27.1-33.6
Non-Metro	798	338	44.6	41.1-48.2	75	9.4	7.5-11.6	53	6.2	4.7- 8.0	332	39.8	36.5-43.3
Income													
14,999 or less	239	179	74.8	68.8-80.0	14	5.6	3.3- 9.3	5	2.4	1.0- 5.7	41	17.1	12.8-22.6
15,000-24,999	177	115	64.5	57.1-71.3	19	11.3	7.3-17.2	7	3.5	1.7- 7.2	36	20.6	15.2-27.4
25,000-49,999	322	161	50.5	45.0-55.9	39	12.2	9.1-16.3	28	8.4	5.8-11.9	94	28.9	24.2-34.1
50,000 or more	742	225	31.1	27.8-34.5	70	9.2	7.4-11.5	68	8.9	7.1-11.2	379	50.8	47.2-54.4
WIC recipient													
No	1010	363	37.1	34.1-40.2	102	10.1	8.4-12.1	91	8.6	7.1-10.5	454	44.2	41.1-47.3
Yes	537	353	66.2	62.1-70.2	47	8.6	6.5-11.4	21	3.9	2.5- 5.9	116	21.2	17.9-24.9
Mother on Public Insurance													
No	1011	365	37.1	34.2-40.2	96	9.3	7.6-11.2	94	9.1	7.5-11.0	456	44.5	41.5-47.6
Yes	542	356	66.2	62.1-70.1	53	9.9	7.6-12.7	18	3.2	2.0- 5.0	115	20.7	17.5-24.4

**Data in this table are recoded responses to survey question 3

# Use caution in interpreting cell sizes less than 50.
N = Cell Size, % = Percentage, C.I.(95%) = Confidence Interval (at 95 % probability level).
The percentages shown are weighted percentages, designed to reflect the entire population of Minnesota women having a live birth.

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List of Appendices

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Appendix F – Abstraction to Follow-up Flow Chart

Appendix G – Minnesota Folic Acid Guidelines for the Prevention of Neural Tube Defects (NTDs)

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Appendix A – Minnesota Birth Defects Coding List

Central Nervous System	**ICD-9 Code**
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
Single ventricle	745.3
Ventricular septal defect	745.4
Atrial septal defect	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 weight =>2500 grams or note if unable to exclude <2500 grams infants	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

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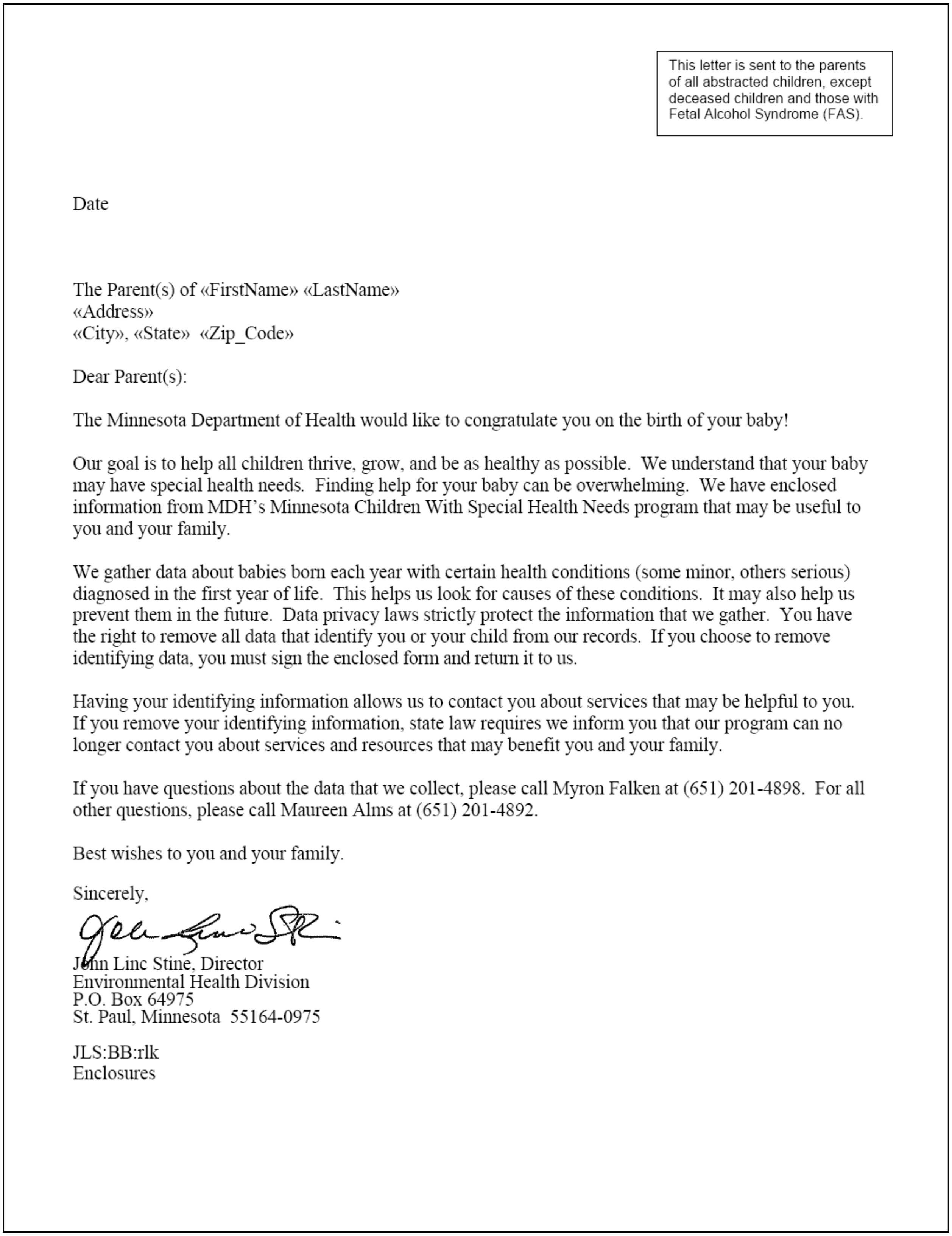
Appendix B – Birth Defects Parent Letters



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.

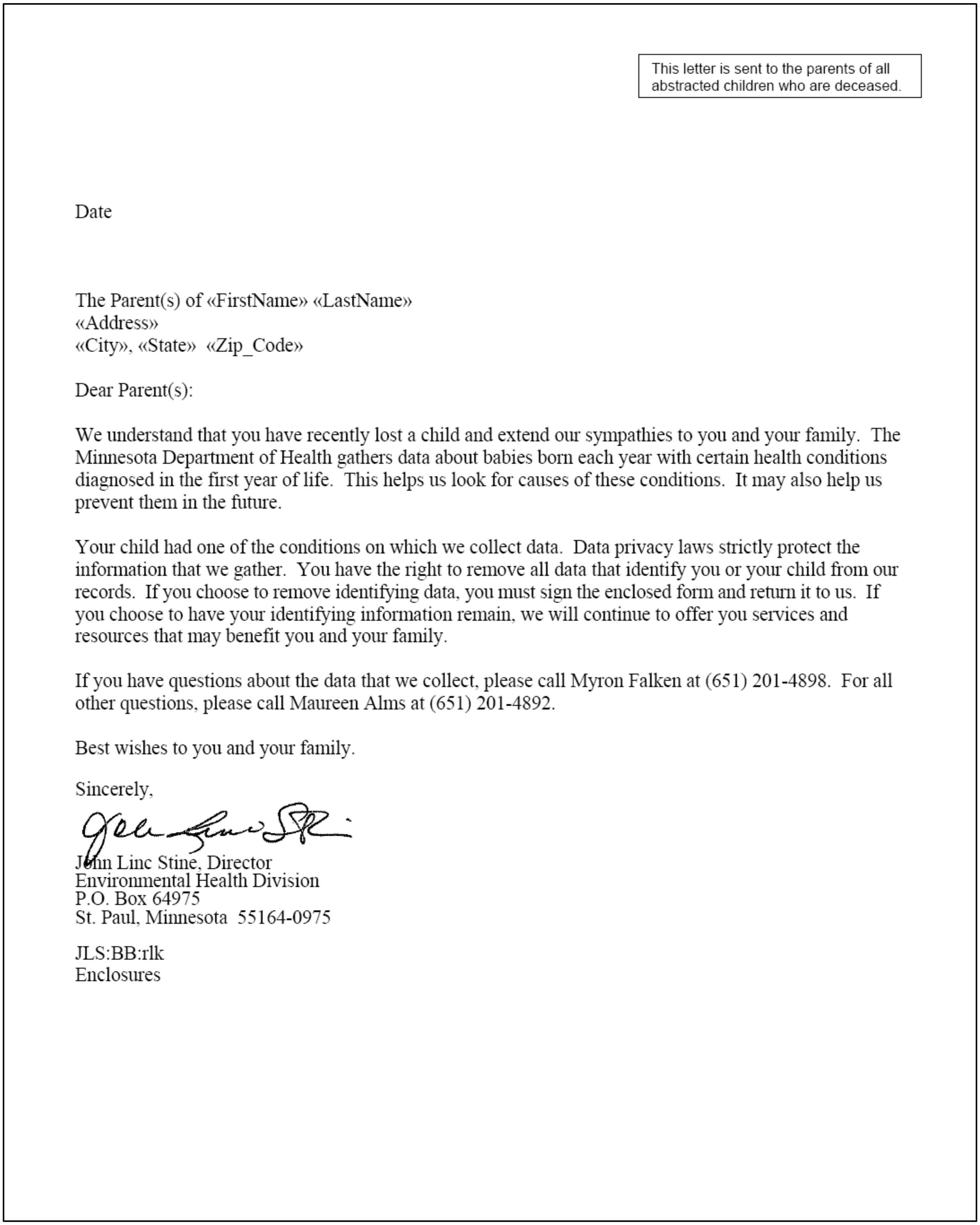
If you have questions about the data that we collect, please call Myron Falken at (651) 201-4898. For all other questions, please call Maureen Alms at (651) 201-4892.

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



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

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

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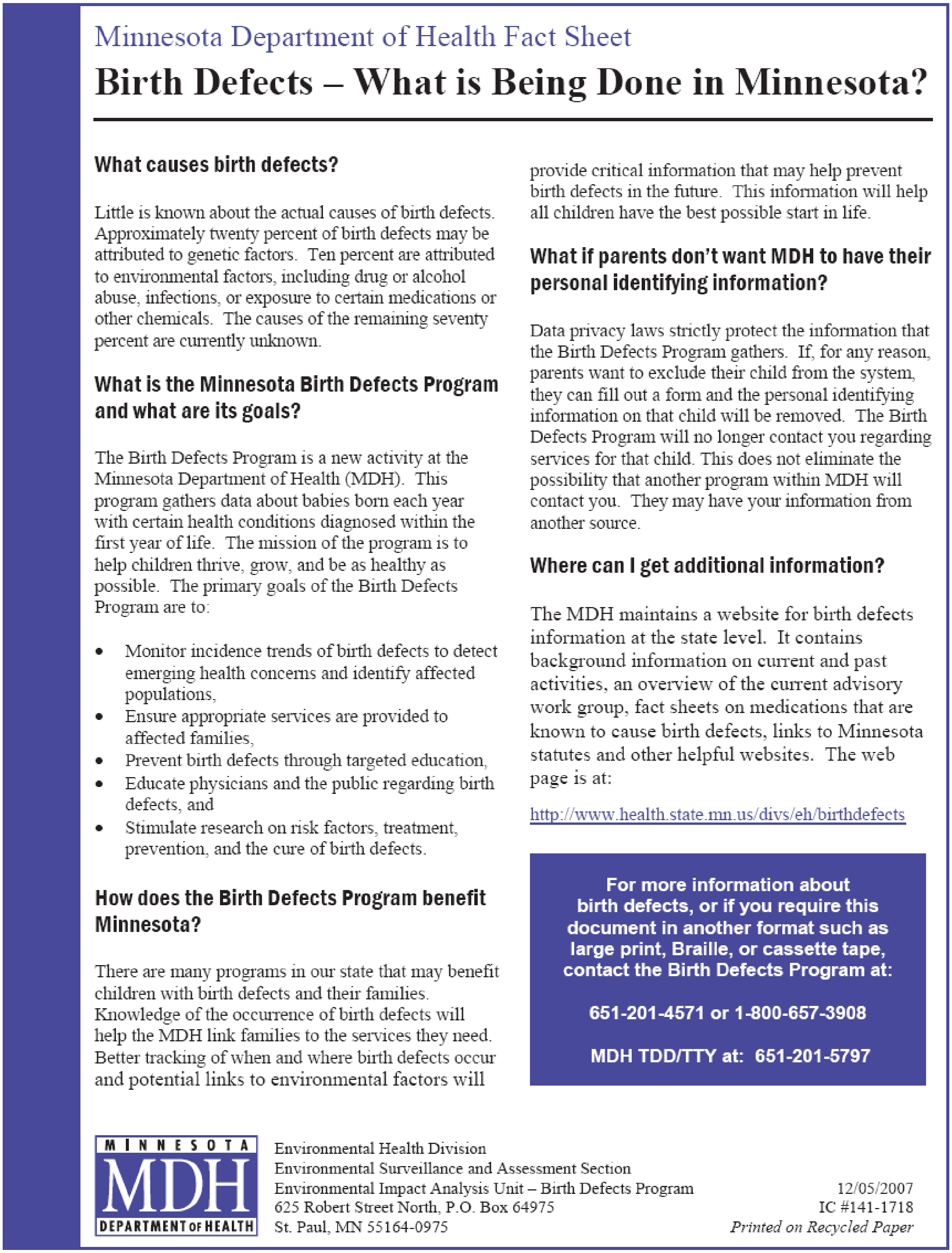
Appendix C – Birth Defects Program Fact Sheet



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:

651-201-4571 or 1-800-657-3908

MDH TDD/TTY at: 651-201-5797

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

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Appendix D – MCSHN Program Brochure

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.

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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

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

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.

<u>By signing below, you acknowledge:</u>

- 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

Printed on Recycled Paper
April 2006

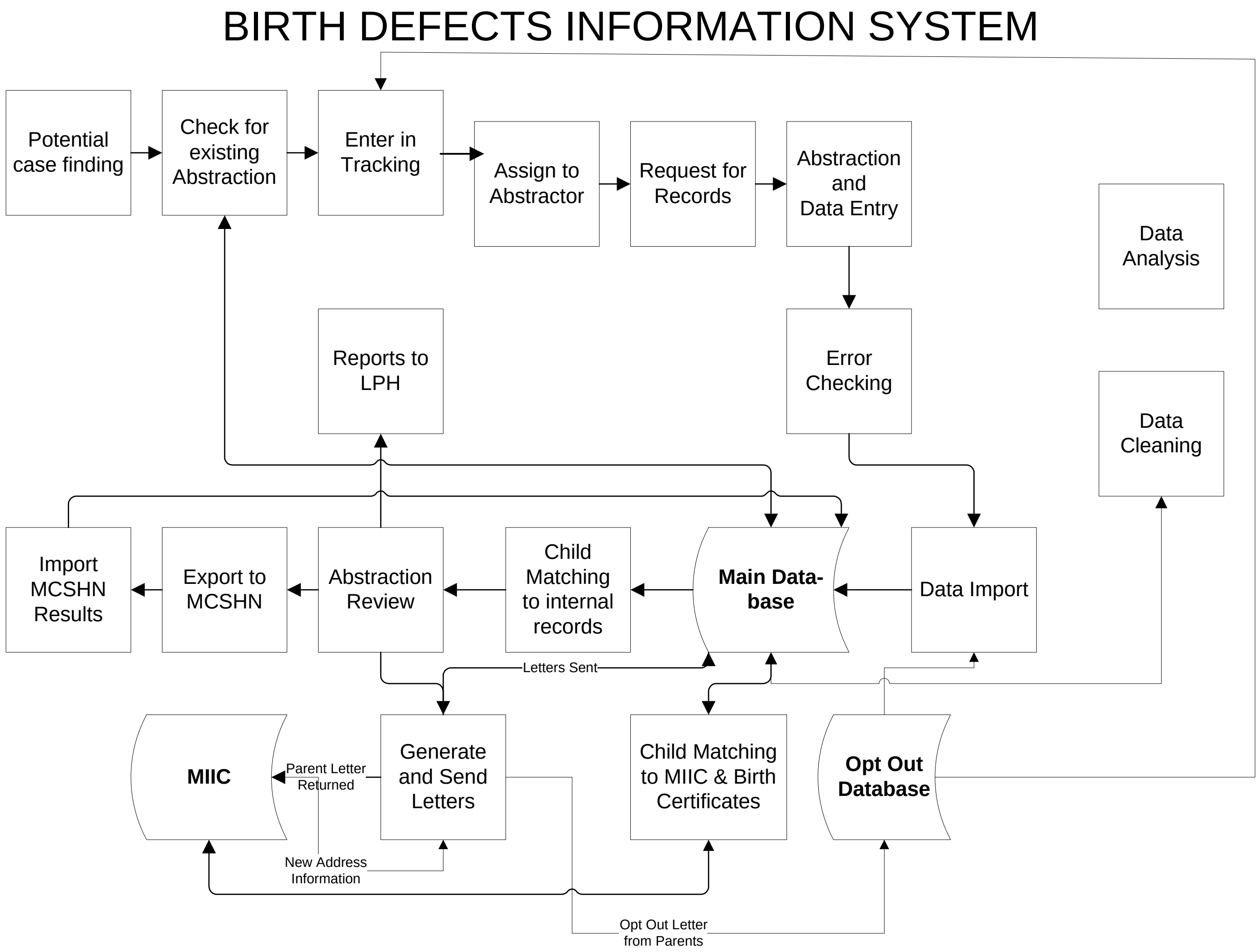
For more information about the Birth Defects Program please call: (651) 201-4892; or 1 (800) 657-3908; or TTD (651) 201-5797.

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

For office use only: ____________________

<u>Original</u>: Birth Defects Information System **<u>Copy</u>:** MCSHN

Appendix F: Abstraction to Follow-up Flow Chart



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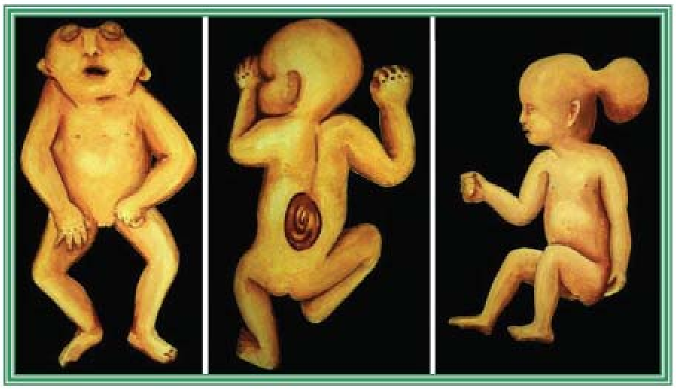
Minnesota's Folic Acid Guidelines for the Prevention of Neural Tube Defects (NTDs)



FOLIC ACID CAN PREVENT 50 TO 70 PERCENT OF NTDs

—50% OF ALL PREGNANCIES ARE UNPLANNED—

All women of childbearing age should maintain a proper level of folic acid.

GENERAL RECOMMENDATIONS

ALL WOMEN OF CHILDBEARING AGE SHOULD TAKE **400 MCG** OF FOLIC ACID PER DAY **AND** RECEIVE A MEDICAL HISTORY TO DETERMINE NTD RISK

No Prior NTD History	**Recommend:** • Continue taking **400 mcg** of folic acid per day.
High Risk • Family History of an NTD • Prior NTD Birth	**Recommend:** • Increase dosage to **4000 mcg** of folic acid daily—starting at least one month BEFORE pregnancy.

<<SPECIAL CONSIDERATIONS ARE COVERED ON BACK>>

MINNESOTA MDH DEPARTMENT OF HEALTH

Environmental Health Division
Environmental Surveillance and Assessment Section
Environmental Impacts Analysis Unit – Birth Defects
P.O. Box 64975
St. Paul, Minnesota 55164-0975

FOR MORE INFORMATION ABOUT BIRTH DEFECTS AND MINNESOTA'S BIRTH DEFECTS PROGRAM SEE:

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

COMMON QUESTIONS ABOUT FOLIC ACID SUPPLEMENTATION

Can a woman take too much folic acid?

- Folic acid is a water-soluble vitamin, so any excess intake is usually excreted in the urine.
- There is no clear evidence of folic acid-induced neurotoxicity in humans or increased frequency of seizures in epileptics at a folic acid dose of 5000 mcg or less.
- Physicians should weigh risks and benefits of supplementing anyone who has cancer, or is at risk of harboring precancerous growths because of family history, genetics, or advanced age.

Should a high-risk woman take additional multi-vitamins to reach the proper dosage?

- Higher levels of supplementation should be achieved by taking a prescription for folic acid and not by taking excess multi-vitamins due to the potential risk to the fetus and mother from excess vitamin A and D levels.
- For a daily dose of 4000 mcg, it is recommended that the patient take 1000 mcg four times per day to maximize the absorption of folic acid.

What are the special considerations for PERNICIOUS ANEMIA?

- The Institute of Medicine (IOM) has set an upper limit of 1000 mcg of folic acid for all people, to avoid potential masking of pernicious anemia. However, because the prevalence of pernicious anemia for females in the childbearing years is very low, consumption above the IOM limit is unlikely to produce adverse effects due to pernicious anemia. Physicians may want to obtain a baseline B_{12}, while monitoring folic acid response to supplementation.

What are the special considerations for women taking seizure medications?

- A number of drugs can interfere with the pharmacokinetics of folic acid, such as: Anti-Seizure Medications (even if this class of medications is used to treat problems other than seizures), Barbiturates, Methotrexate, Trimethoprim, Metformin, Triamterene and Sulfasalazine.
- Antiepileptic drugs (AEDs) have been associated with an increased risk in congenital malformations.
- Women taking some AEDs may have low levels of serum folic acid. Conversely, some women may have lower serum AED levels while taking folic acid supplementation. Monitoring anti-seizure medication levels and dose adjustment may avert these problems.

What are the special considerations for women after undergoing bariatric surgery?

- Previous bariatric surgery has not been associated with adverse perinatal outcome.
- Folic acid, B_{12} and iron deficiency anemia are common following bariatric surgery, but folic acid deficiency is almost always corrected with multi-vitamins alone.

What other groups of women may have increased risks?

- Obese women (BMI 30 or above) and those with diabetes may need red blood cell folate levels monitored.
- Non-white, young, less educated, and lower-income women are the least likely to report taking folic acid daily.
- Hispanic/Latina women have a risk 1.5 to 3 times higher than non-Hispanic white women for having a child affected by an NTD.

For detailed information and references for the questions above,
please refer to the companion document:

MINNESOTA'S FOLIC ACID GUIDELINES FOR THE PREVENTION OF NEURAL TUBE DEFECTS (NTDS)
LITERATURE REFERENCE MANUAL

This document can be found at: *www.health.state.mn.us/divs/eh/birthdefects/reports*

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

For more information about birth defects, contact the
Birth Defects program at (651) 201-4899
If you require this document in another format,
such as large print, Braille, or cassette tape, call:
651-201-5000 ♦ 1-800-657-3908 ♦ MDH TTY 651-201-5797

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