This document is made available electronically by the Minnesota Legislative Reference Library
as part of an ongoing digital archiving project. http://www.leg.state.mn.us/lrl/lrl.asp

Birth Defects Program

2007 Annual Report

MINNESOTA
MDH
DEPARTMENT OF HEALTH

Environmental Impacts Analysis Unit

May 2008

For more information about birth defects, contact the
Birth Defects Program at (651) 201-4610

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
Or the Minnesota Relay Service TTY 1-800-627-3529

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

Printed on Recycled Paper

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 of 2005, the State of Minnesota statutory language (MS144.2215-2219) authorized the Minnesota Department of Health (MDH) to collect birth defect information. The 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 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. 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 reviewed by the public health nurse 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 referred to 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: 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. Background of the Minnesota Birth Defects program is included as well.

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. 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 program activities. Therefore, 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. In year three (June 2007 - May 2008), the MDH was awarded $120,000 for the year. In the past year, the Birth Defects program 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)
- 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 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 at a limited number of birthing hospitals began in August 2005. The Birth Defects 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 fifty percent of all births in Minnesota. As funding becomes available, the program plans to expand abstraction to all hospital Neonatal Intensive Care Units (NICUs) and birthing hospitals statewide.

Historically, birth defects are listed on the birth certificates and used to describe trends nationally. Because information on the birth certificate is passively collected, the number of cases identified is generally much lower than that which would be determined using the active surveillance method currently used by the Birth Defects program. Therefore rates generated using birth certificate reporting should be used with caution. More information on birth defects data on birth certificates is included in "Completeness of Case Finding" on page 7.

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 Med. Center
	Hennepin County Medical Center
	KDWB Pediatric Physicians
	Methodist Hospital HealthSystem Minnesota
	North Memorial Med 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

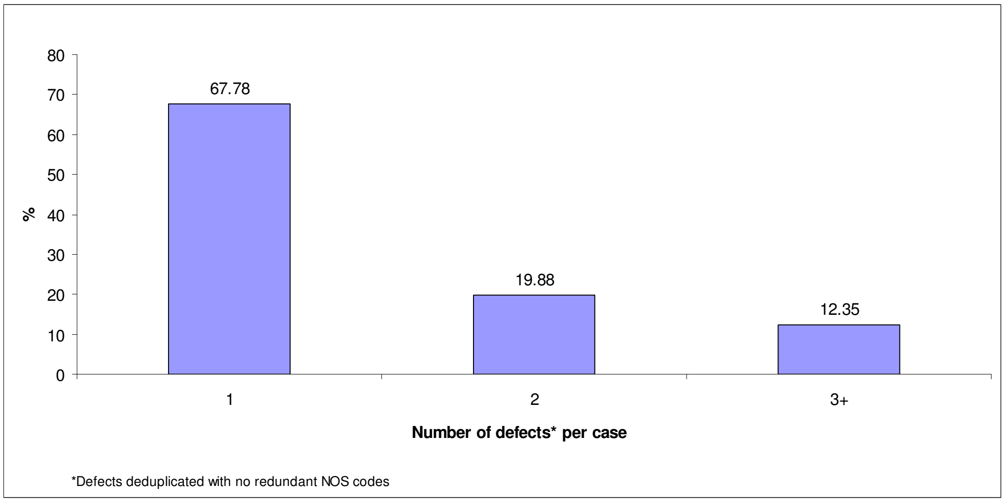
Participating hospitals regularly notify the Birth Defects program of children discharged from their hospital with a potential birth defect. The potential cases are appended to a tracking table to check for any previous abstraction for the same child and defect. If the case is new or a new defect is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

The Birth Defects program uses the Minnesota Birth Defects Coding List (Appendix A). Conditions include 44 nationally reported birth defects and a single ventricle defect. The list of nationally reported birth defects was developed collaboratively by the CDC and the National Birth Defects Prevention Network (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 and validated by the Public Health Nurse lead worker 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.

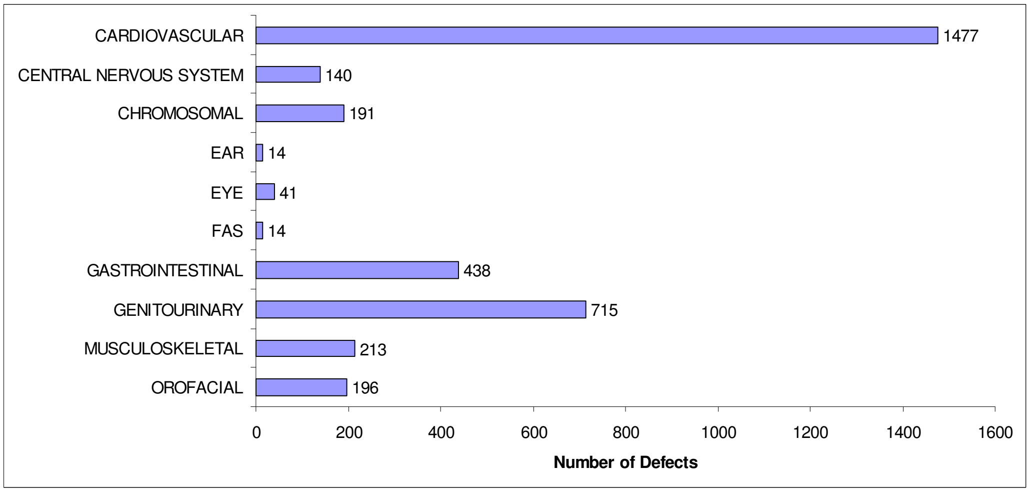
As of January 1, 2008, 2284 cases were validated and entered into BDIS which includes children born in 2005, 2006 and 2007. Because children may have additional birth defects diagnosed up to their first birthday, these 2284 cases incurred 2337 unique abstractions and a total of 3439 unique birth defects. Figure 1 shows the percentage of cases with one or multiple birth defects. About 32 percent of cases in BDIS have more than one birth defect. Figure 2 shows the breakdown of unique birth defects by groups of defect. The majority of validated birth defects were cardiovascular (43 %), followed by genitourinary (21%) and gastrointestinal (13%) defects.

Figure 1: Number of birth defects per case among cases born in 2005, 2006 and 2007; reviewed by 1/1/2008.



*Defects deduplicated with no redundant NOS codes

Figure 2: Number of birth defects by defect group among cases born in 2005, 2006 and 2007; reviewed by 1/1/2008.



Because abstraction began in mid-year 2005 and abstraction facilities were phased in throughout the two years, the data does not include all possible cases born in 2005 or 2006 who received services at a hospital located in Hennepin or Ramsey counties. In addition, data presented are frequencies; it is not possible to analyze birth year cohort data until the close of the following year due to the inclusion into BDIS of birth defects diagnosed up to a child's first birthday. Estimates of 2006 prevalence rates for select birth defects in Hennepin and Ramsey counties should be available by July 2008.

After entry into BDIS, each validated birth defect case is sent a parent 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 is filled out and returned to the Birth Defects program if parents do not want their child's identifying information included in the BDIS database. Upon receipt of a completed opt-out form, the Birth Defects program removes an individual's personal identifying information from BDIS and sends the family a letter confirming this action. As of April 1, 2008, 103 parents or guardians (4.5%) have returned an opt-out form to MDH requesting that all identifying information pertaining to them and their child be removed from BDIS. There was no significant difference between the major birth defect groups and the opt outs from each group. 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.

The Birth Defects Program collaborates with the Minnesota Fetal Alcohol Syndrome (FAS) Prevention Program and receives some funding from their program. 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 the FAS program's grant objectives. As of April 1, 2008 there were 196 cases abstracted, resulting in 41 confirmed cases of FAS using the FASSLink software. No rates are available, because the Birth Defects program continues to examine data regarding the county of residence for the mothers of the identified cases. This process is complicated by the fact that more than 70 percent of FAS children do not live with their biological parent.

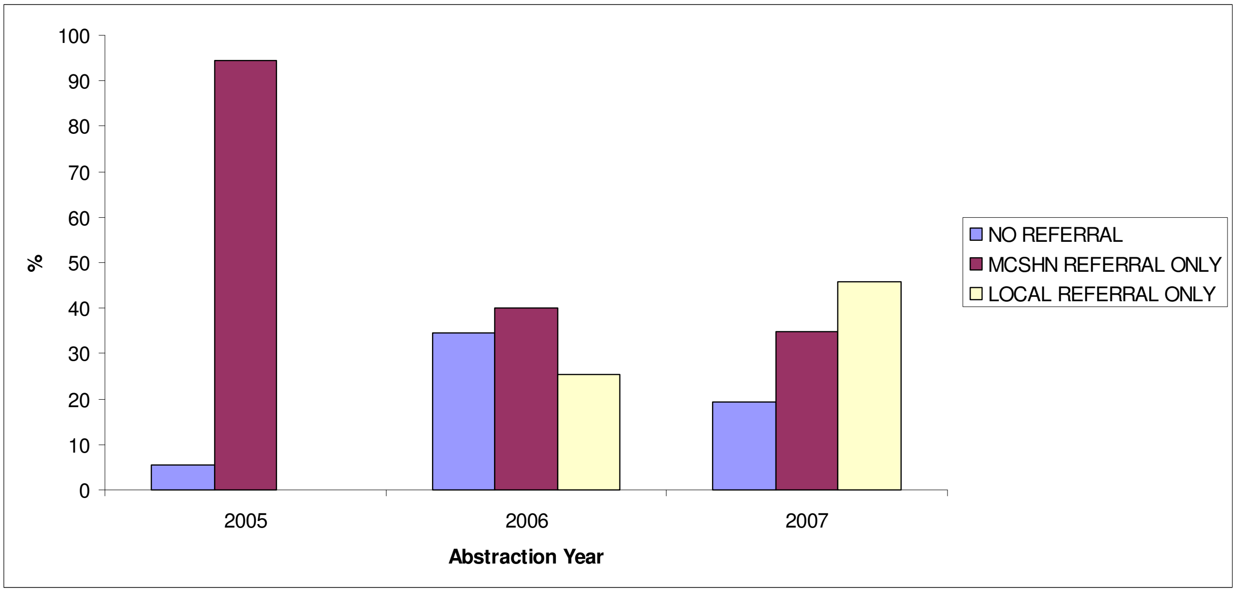
Notification/Referral to Services

All validated cases receive information about MCSHN in the initial letter sent by the Birth Defects program. MCSHN is the state health department program accountable for the performance of core public health functions for children with special health needs. In addition, cases that have not opted-out of BDIS are contacted to ensure appropriate resources are provided to the affected families.

Local public agencies, located in each of Minnesota's 87 counties, provide most of the actual case management and direct services for public health activities in the State of Minnesota. These agencies are encouraged to participate in MDH programs and projects within the limits of their resources. Certain local public health agencies have agreed to take notification of BDIS cases; they are informed by the Birth Defect program when a case in their county is diagnosed with a birth defect. As of January 1, 2008, 53 local public health agencies were receiving notification of children with select birth defects in their counties. The remaining cases are referred to MCSHN, who attempt to connect children and families with necessary public health services. During 2008, staff from the Birth Defects program will met with the counties who are not currently receiving notices of cases entered into the BDIS to encourage their participation. Figure 3 shows the increasing participation of local public health agencies in the follow-up of cases born in 2005 and 2006, 2007 and reviewed as of January 1, 2008.

The increase in no-referrals observed in 2006 resulted from some problems associated with the start-up of the system and historic data coming in to the system. For example, there were children who were over 1 year old. Since these children were over 1 year old, the program has made the policy decision to not refer them because they have likely already received available services. Even though all children are not personally contacted with a referral/notification, all families are sent an informational packet listing available resources and referrals. In addition, there were opt outs, deceased, and undeliverable addresses contributing to the number of "no referrals". Due to efficiencies in the system, the number of "no referrals" decreased in 2007 and we expect this trend to continue. MDH will continue to make every effort to ensure that all children are contacted in a timely manner.

Figure 3: Case follow-up patterns among cases born in 2005, 2006 and 2007; Reviewed by 1/1/2008



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. Potential cases are checked against existing data and appended to a tracking table in order to check for previous abstractions of the same defect. The records-tracking database includes information on dates, hospitals, and other medical record information for each case. In addition to ensuring that all medical records are reviewed and completely abstracted, the records-tracking database is used to determine the average times between birth, abstraction activities, and notification or referral. This data allows the Birth Defects 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 in 2005 and 2006, 2007 reviewed as of January 1, 2008 are reported in Table 2. 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. This, 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 two years of operation, at just under a month. Overall, the time from the birth of a case to the time affected families received information from the Birth Defects program about available services was over 5 months for cases born in 2005, and less than 4 months for cases born in 2006.

Table 2: Average time between events completed by the Birth Defects program Among cases born in 2005 and 2006, 2007 reviewed by 1/1/2008

Time in Weeks from Major events tracked in BDIS, cases reviewed by January 1, 2008								
	Birth to Hospital Discharge		Hospital Discharge to Abstraction		Abstraction to Referral to MCSHN		Abstraction to Letter* sent	
Abstraction year	N	Weeks	N	Weeks	N	Weeks	N	Weeks
2005	176	2.5	175	11	174	2	182	3
2006	925	3	922	10	383	3	956	4
2007	1116	3	1115	10	397	3	1134	4

*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. Currently, the Birth Defects program uses the following sources for case finding in addition to medical records:

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

Many studies have shown that birth defects are severely under-reported on birth certificates. Appendix G lists the total number of each birth defect in Minnesota for 2000 - 2006 as listed on Minnesota birth certificates. Appendix H provides the rate of birth defects per 10,000 births in Minnesota based on birth certificate data. Because birth certificates are not a very accurate source for birth defect data, high confidence should not be placed in these figures to represent the actual rates of birth defects in the state of Minnesota. However, birth certificates can be matched to BDIS records to determine completeness of our active surveillance system and will be a means of case finding.

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 is not identified duplicates result from a child being seen multiple times and 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. This 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 cannot be used for patient referrals because the data is de-identified and greater than one year old. Birth Certificates and Medicaid data were used for case finding for 2007, 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

Of the 500 records abstracted on paper from 2005 – 2006, five percent (25) were 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. Each check box must be verified to be able to confidently determine whether the data is not found or that the item was not assessed. Accuracy was 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. After the birth defect epidemiologist reviewed the major and minor discrepancies, the public health nurse and abstractors met to discuss ways in which to help eliminate errors in the abstracting process. Policies and procedures were developed to help eliminate future errors in data collection.

During 2006, the Birth Defects program switched from paper to laptop data collection by the abstractors. A five percent sample of selected medical records will be completed using the new collection process in 2008.

Data Cleaning and Retention

The BDIS database, a relational database consisting of multiple tables, is 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, Birth Defects 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 is handled consistent with all applicable MDH policies and the Minnesota Data Practices Act.

Folic Acid Prevention Activities

The Birth Defects program continues to work with the Minnesota Folic Acid Council (FAC) to recruit collaborating partners and pursue educational opportunities. A folic acid media campaign, developed by Birth Defect program staff and endorsed by FAC, was designed for the 2006 Minnesota State Fair. The campaign used a poster to promote the use of folic acid to prevent birth defects of the spine and brain. A daily intake of 400 mcg is recommended for all women, regardless of pregnancy status.

During 2007, Minnesota's Folic Acid Guidelines for the Prevention of Neural Tube Defects (NTDs) were developed. The Minnesota Department of Health's 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 for these guidelines. The Guidelines for the Prevention of NTDs can be found in Appendix I and at: http://www.health.state.mn.us/divs/eh/birthdefects/reports/faguidelines.pdf .

In April of 2007, MDH, local public health organizations and providers in Minneapolis and St. Paul, and a coalition of Catholic parishes that serve primarily Hispanic populations planned and produced a Latina Mother-Baby Group workshop to address health concerns in the Hispanic community. The workshop, conducted entirely in Spanish, trained key individuals in the Hispanic community about access to health care and awareness of public health risks. The Birth Defects program and the FAC were interested in reaching out to this population because Hispanic women have significantly higher rates of neural tube defects in their newborns. These trained community leaders now have skills to better communicate and implement effective methods for preventing birth defects in their community. MDH is committed to reaching out to communities with significant health disparities, and this conference was an important step in bridging the communication gap between public health information and local community leaders. Collaborating partners included MDH Office of Minority and Multicultural Health, the MDH Community and Family Health Division, and a range of public and private organizations.

2004 and 2006 Folic Acid Survey

During 2004 and 2006 the Behavioral Risk Factor Surveillance System (BRFSS) a state-based system of health surveys that collects information on health risk behaviors, preventive health practices, and health care access primarily related to chronic disease and injury included questions about Folic Acid. These questions were designed and tested by the Centers for Disease Control and are used nation wide. In Minnesota as indicated by the following table, about 68 – 65 percent of women in Minnesota took a vitamin in 2004 and 2006 respectively, with 85 percent of the women indicating that they were multivitamins. When asked whether any of the vitamins contained Folic Acid, only 33 percent in 2004 and 22 percent in 2006 indicated that they knew their vitamins contained Folic Acid. Only about 50 percent of the women in both years of the survey knew that Folic Acid was needed to prevent birth defects.

Table 3: Folic acid questions answered by women in 2004 and 2006 from the BRFSS survey

Question	2004	2006
Currently taking Vitamin (yes)	68.3	65.0
Are they Multivitamins (yes)	85.0	84.7
Do they contain Folic Acid (Don't Know)	33.5	23.2
Folic Acid prevents birth defects (yes)	47.6	51.4

The results of the BRFSS survey indicate that MDH needs to continue to develop educational messages about the benefits of folic acid for the general population

List of Appendices

Appendix A – Minnesota Birth Defects Coding List

Appendix B – Birth Defects Parent Letters

Appendix C – Birth Defects Program Fact Sheet

Appendix D – MCSHN Program Brochure

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

Appendix F – Abstraction to Follow-up Flow Chart

Appendix G – Number of Birth Defects from MN Birth Certificates

Appendix H – Rates of Birth Defects from Minnesota Birth Certificates

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

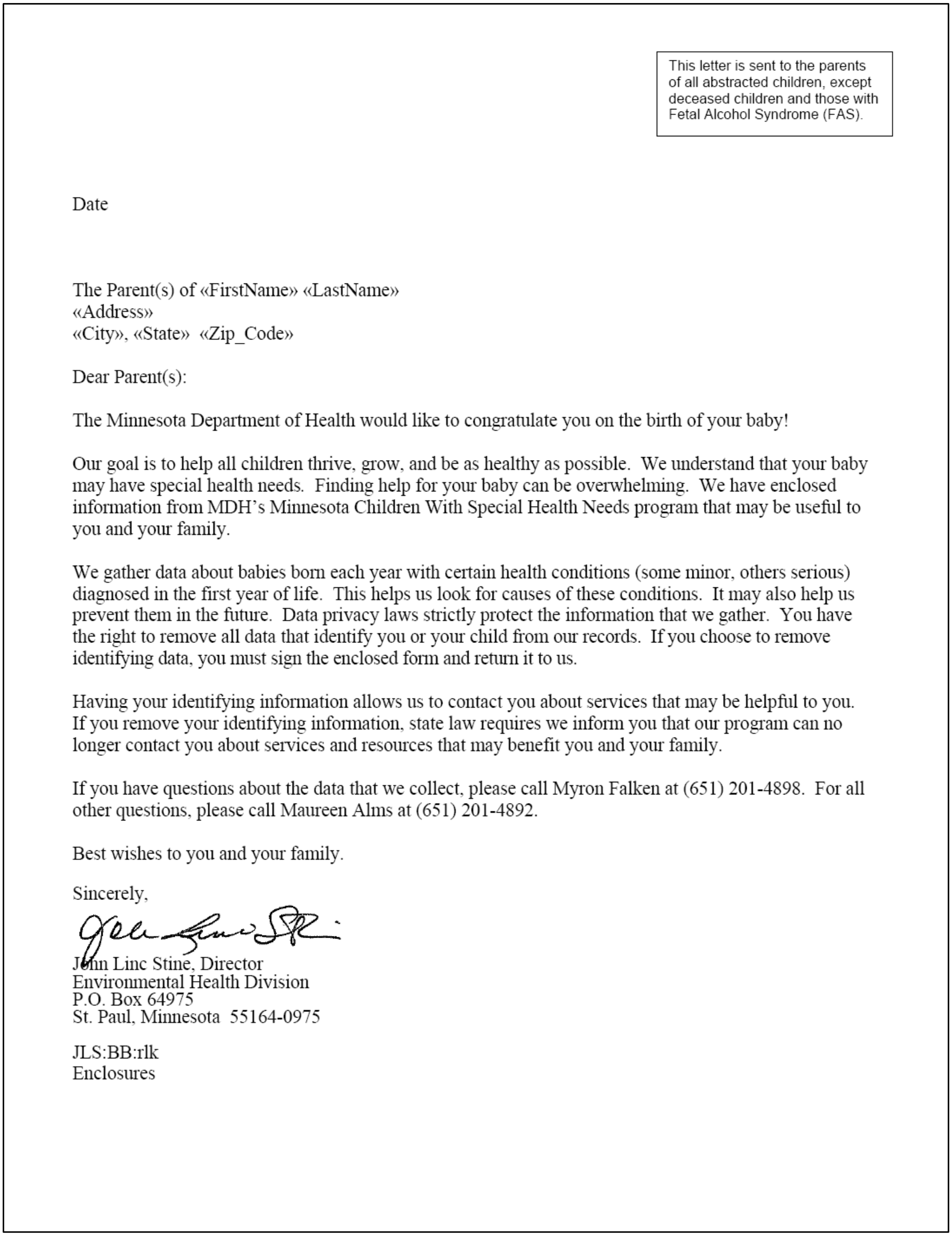
Intentionally Left Blank

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
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
Amniotic bands	No code

Intentionally Left Blank

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.

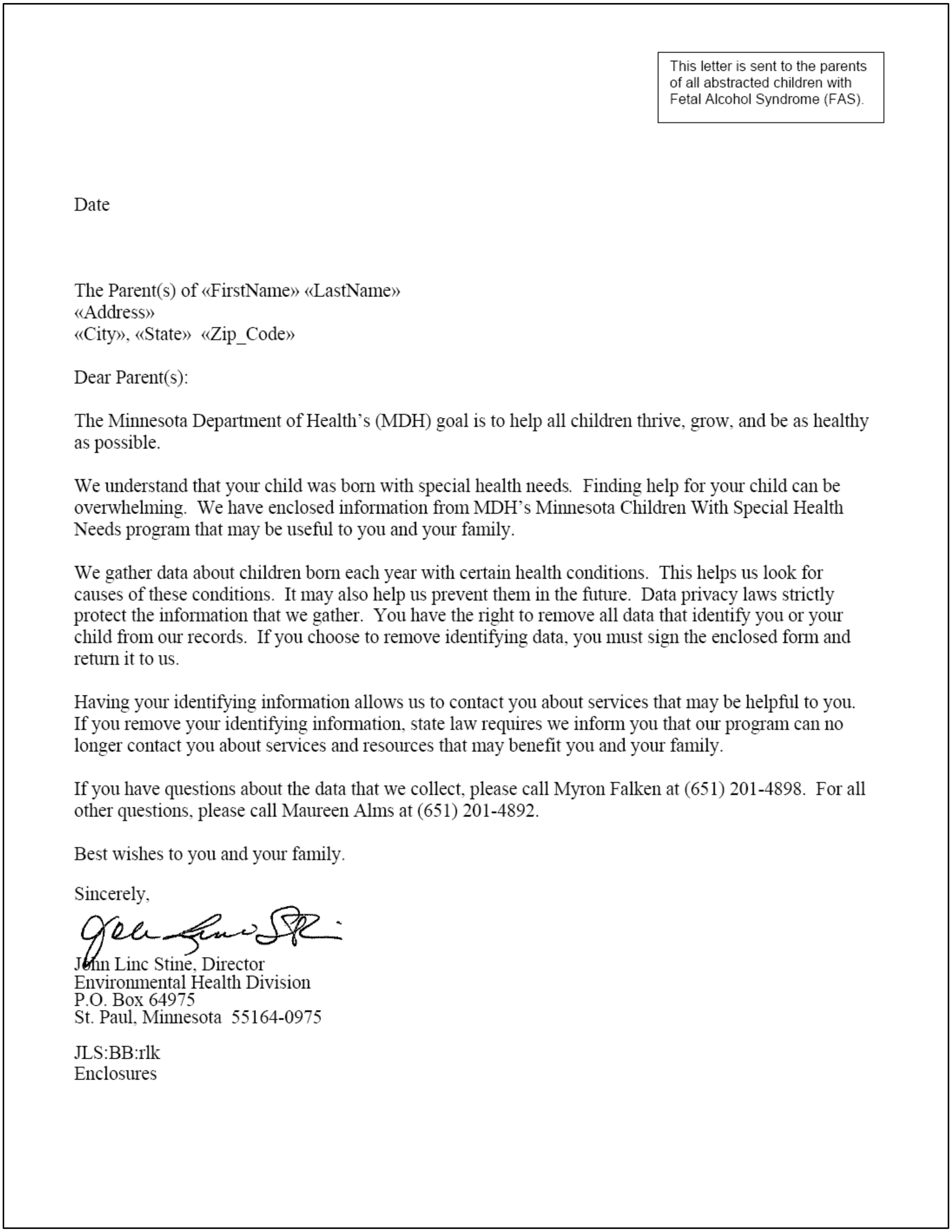
If you have questions about the data that we collect, please call Myron Falken at (651) 201-4898. For all other questions, please call Maureen Alms at (651) 201-4892.

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.

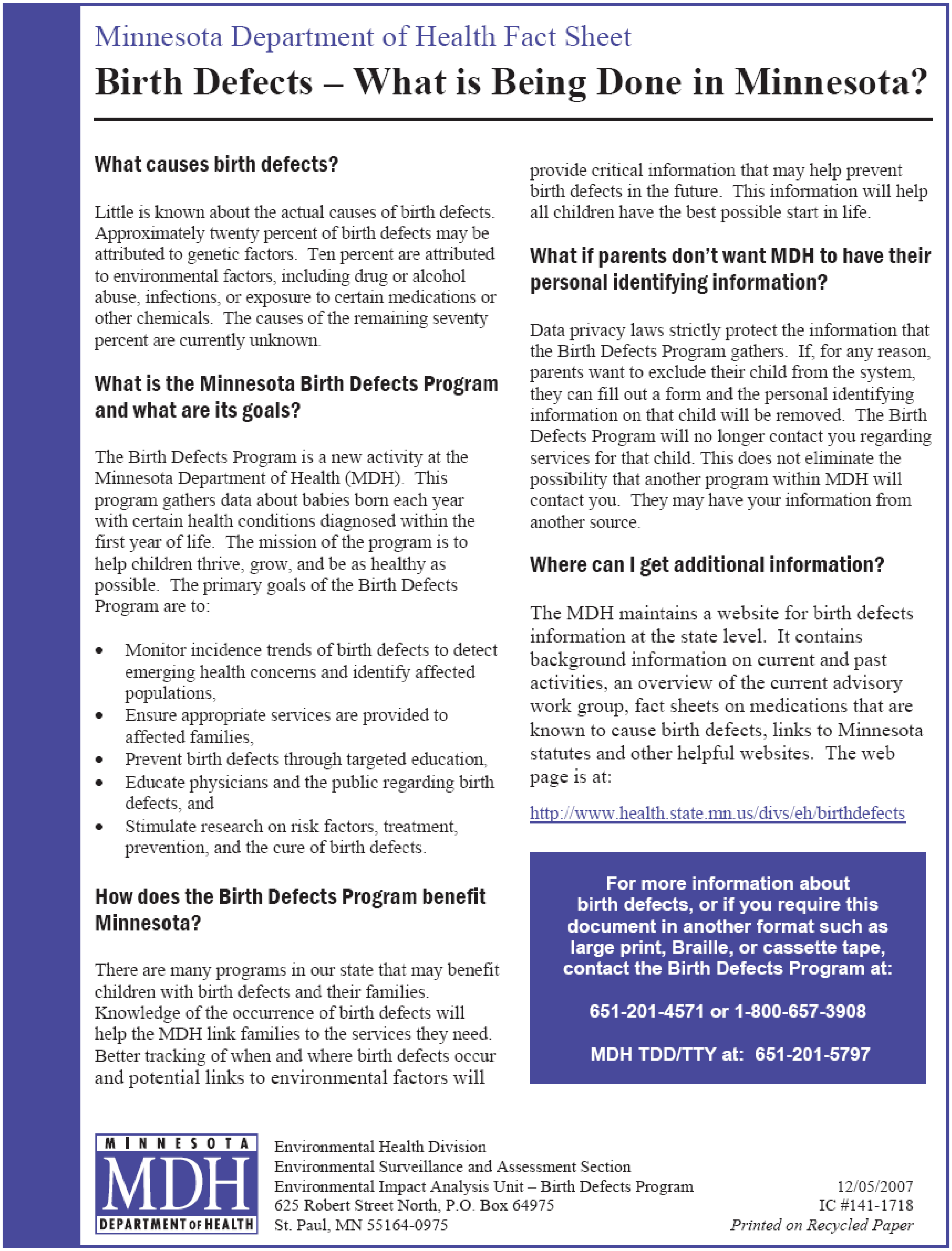
Sincerely,

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

JLS:BB:rlk
Enclosures

Intentionally Left Blank

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

12/05/2007
IC #141-1718
Printed on Recycled Paper

Intentionally Left Blank

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.

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

Intentionally Left Blank

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

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.

MINNESOTA
MDH
DEPARTMENT OF HEALTH

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

Printed on Recycled Paper
April 2006

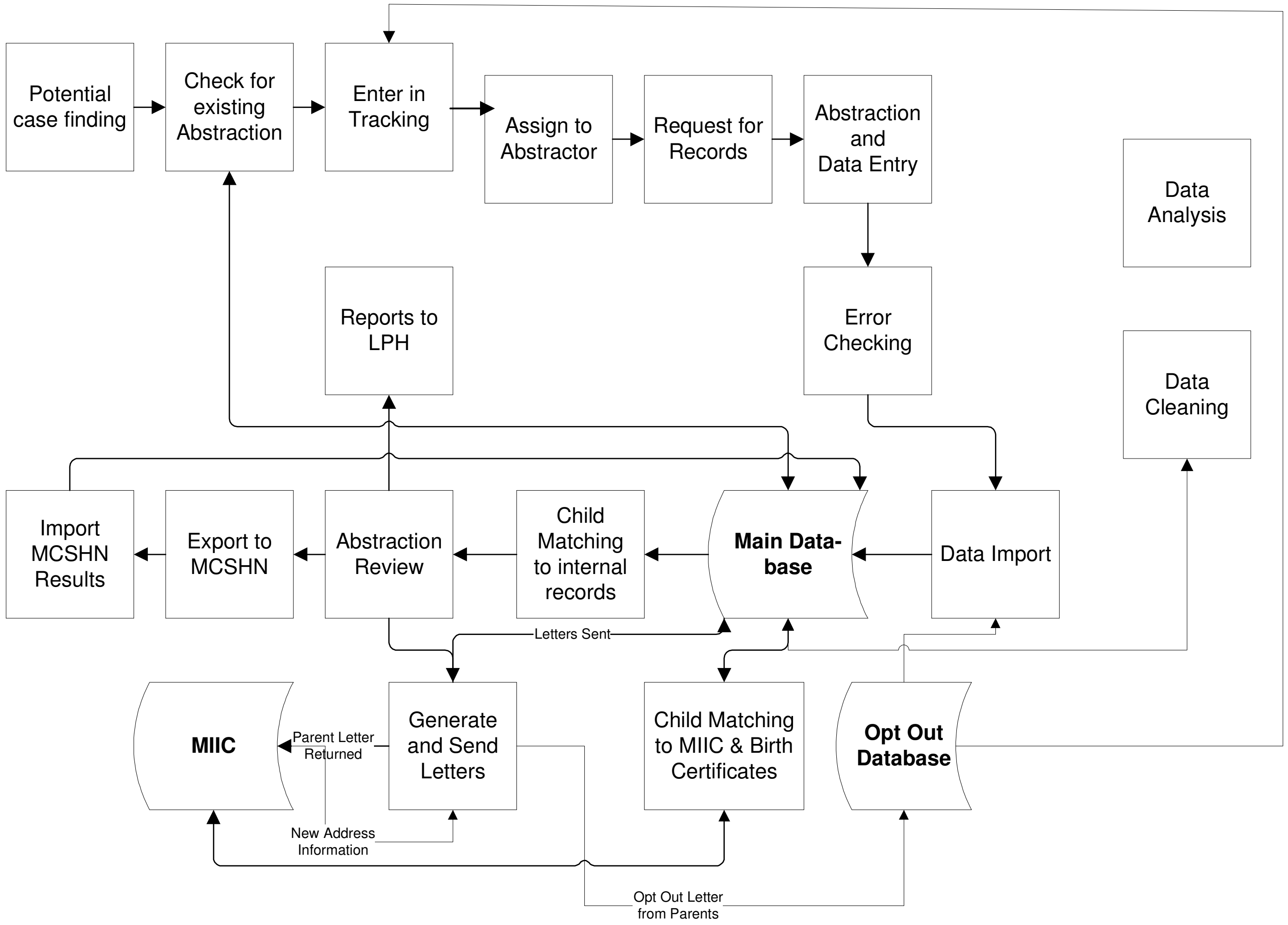
For more information about the Birth Defects Program please call: (651) 201-4892; or 1 (800) 657-3908; or TTD (651) 201-5797.

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

For office use only: ____________________

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

Appendix F: Abstraction to Follow-up Flow Chart


BIRTH DEFECTS INFORMATION SYSTEM

Intentionally Left Blank

Appendix G – Number of Birth Defects by specific defect from MN Birth Certificates; 1997 - 2007

	Number of Birth Defects									
	1998	**1999**	**2000**	**2001**	**2002**	**2003**	**2004**	**2005**	**2006**	**2007**
Anencephalus	8	9	11	7	6	10	7	10	9	9
Spina Bifida	9	16	14	10	10	13	5	6	14	10
Hydrocephalus	16	24	10	12	12	21	7	12	10	12
Microcephalus	5	5	5	3	3	5	2	6	1	5
Central Nervous System	20	17	19	21	21	25	24	20	20	19
Heart Malformations	49	62	70	56	58	73	73	68	69	77
Circulatory/Respiratory	52	48	54	47	42	57	65	44	35	53
Rectal Atresia/Stenosis	4	4	9	2	6	5	5	4	10	2
Tracheo-Esophageal	13	11	21	7	9	5	7	5	3	6
Omphalocele/Gastroschisis	14	18	20	20	16	13	12	23	20	27
Gastrointestinal	20	34	21	16	24	21	24	25	24	16
Malformed Genitalia	23	21	29	24	26	24	23	27	24	19
Renal Agenesis	6	4	7	11	6	15	9	8	5	5
Urogenital	101	93	93	88	74	97	93	85	80	100
Cleft-Lip/Palate	61	56	60	63	66	45	53	57	67	43
Polydactyly	40	37	44	32	26	27	37	35	48	27
Club Foot	27	34	43	39	44	36	51	40	45	47
Diaphragmatic Hernia	9	10	9	6	7	8	6	9	9	8
Musculoskeletal	97	112	100	80	74	65	73	65	69	77
Down Syndrome	34	34	30	33	28	29	40	46	30	45
Chromosome	26	52	41	20	27	26	26	26	30	32
Other	249	231	252	234	269	258	237	294	241	294
Total Number of Defects	883	932	962	831	854	878	879	915	863	886
Total Births	65,207	65,953	67,451	66,617	68,178	70,191	70,728	70,920	73,189	73,221

Intentionally Left Blank

Appendix H – Rates of Birth Defects (per 10,000) from Minnesota Birth Certificates; 2000 - 2007

Birth Defect	Minnesota Birth Certificates							
	2000	2001	2002	2003	2004	2005	2006	2007
Anencephalus[1]	1.6	1.1	.88	1.4	1.0	1.4	1.2	1.2
Spina Bifida	2.1	1.5	1.5	1.9	.70	.84	1.9	1.4
Hydrocephalus	1.5	1.8	1.8	3.0	1.0	1.7	1.4	1.6
Microcephalus	.74	.45	.44	.70	.30	.84	.14	.68
Central Nervous System	2.8	3.2	3.1	3.6	3.4	2.8	2.7	2.6
Heart Malformations	10.4	8.4	8.5	10.4	10.3	9.6	9.5	10.5
Circulatory/Respiratory	8.0	7.1	6.2	8.1	9.2	6.2	4.8	7.3
Rectal Atresia/Stenosis	1.3	.30	.88	.70	.70	.56	1.4	.27
Tracheo-Esophageal	3.1	1.1	1.3	.70	1.0	.70	.41	.82
Omphalocele/Gastroschisis	2.9	3.0	2.3	1.9	1.7	3.2	2.7	3.7
Gastrointestinal[2]	3.1	2.4	3.5	3.0	3.4	3.5	3.3	2.2
Malformed Genitalia[3]	4.3	3.6	3.8	3.4	3.3	3.8	3.3	2.6
Renal Agenesis	1.0	1.6	.88	2.1	1.3	1.1	.68	.68
Urogenital[4]	13.8	13.2	10.9	13.8	13.2	12	10.9	13.2
Cleft-Lip/Palate	8.9	9.5	9.8	6.4	7.5	8.0	9.2	5.9
Polydactyly	6.5	4.8	3.8	3.8	5.2	4.9	6.6	3.7
Club Foot	6.4	5.8	6.5	5.1	7.2	5.6	6.2	6.4
Diaphragmatic Hernia	1.3	.90	1.0	1.1	.80	1.3	1.2	4.38
Musculoskeletal[5]	14.8	12.0	10.9	9.3	10.3	9.1	9.5	10.6
Down Syndrome	4.4	4.9	4.1	4.1	5.7	6.5	4.1	6.2
Chromosome[6]	6.1	3.0	4.0	3.7	3.7	3.7	4.1	4.4
Other[7]	37.4	35.1	39.5	36.8	33.5	41.4	33.0	40.3

* *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 I – Minnesota's Folic Acid Guidelines for the Prevention of Neural Tube Defects (NTDs) (two-sided)

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*

---

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

Funded by CDC Grant:
#U50/CCU521124
Printed on Recycled Paper
Released: January 2008
IC #141-1800