WISCONSIN BIRTH DEFECT PREVENTION AND SURVEILLANCE PROGRAM Report to the Legislature

June 2012

BACKGROUND

In the late 1980s, Wisconsin legislation created the Birth Defects Outcome and Monitoring Program. Physicians submitted paper-reports for birth defects, developmental or acquired disabilities, or severe sensory impairments of children less than six years old. Through a federal initiative in 1998, the Birth Defects Prevention Act directed the Centers for Disease Control and Prevention (CDC) to work with states to collect and analyze data on birth defects and provide information to the public about the prevention of birth defects. CDC provided funding to states to help achieve this goal.

The Wisconsin Birth Defect Prevention and Surveillance Program (WBDPSP) was established in May 2000, replacing the Birth Defect Outcome Monitoring Program by amending s. 46.82(1) and s.253.13(2) and repealing and recreating Wisconsin statute 253.12 to address limited reporting compliance. The law requires the Department of Health Services (DHS) to establish and maintain an up-to-date birth defects registry of diagnosed birth defects of any Wisconsin child age birth up to two years of age, requires reporting by pediatric specialty clinics and physicians, and protects the confidentiality of children born with birth defects. Although this registry is still a passive reporting system (no penalty for not reporting), it narrowed the reportable birth defects to a prescribed list of 87 conditions* (see endnote); established a 13-member Birth Defect Prevention and Surveillance Advisory Council; initiated primary prevention strategies to help decrease occurrence; provided for education about the prevention of birth defects; developed a system for referrals to early intervention; and limited service provisions.

In September 2000, DHS was awarded a three-year cooperative agreement from the CDC for the development of a secure, web-based Wisconsin Birth Defects Registry (WBDR) and the development of intervention and prevention capacities. This $330,000 grant ($110,000 per year) allowed for: the design of the WBDR, partnerships with two specialty centers to monitor heart defects, and the development of a structure for monitoring and prevention activities. The WBDR was developed in 2003, piloted at five sites, and rolled out statewide in mid-2004. Chapter HFS 116, Wisconsin Birth Defect Prevention and Surveillance System, contains the administrative rules developed by DHS, with an effective date of April 1, 2003.

The WBDPSP is required to maintain a birth defects registry of diagnosed birth defects of any Wisconsin child age birth to two years who is born in Wisconsin and/or receives health care services in Wisconsin.

The WBDR is a secure, web-based system that allows reporters to report one child with a birth defect at a time or upload multiple reports from an electronic medical records system. Reporters may also submit a paper form to the WBDR state administrator for inclusion in the registry. The WBDR collects information on the child and parents, the birth, referral to services, and diagnostic information for one or more of 87 reportable conditions. If parents withhold permission to report, names and addresses are not included in the report.

Physicians and specialty clinics are required reporters; hospitals are voluntary reporters. In practice, reports are usually submitted for multiple physicians by clinics, health care systems

and some hospitals. From mid-2004 through December 31, 2011, the WBDR received reports of 4,891 birth defects from 70 organizations. The parent permission requirement is an administrative barrier for some reporting organizations. In practice, some organizations simply report without attempting to obtain parent permission. This results in only 22% of the reports submitted with permission that therefore include the full name and address of the child. This practice makes it difficult to calculate an unduplicated count of children with birth defects or an unduplicated incidence of any birth defect. It is also nearly impossible to assess if birth defects are clustered in a particular geographic area.

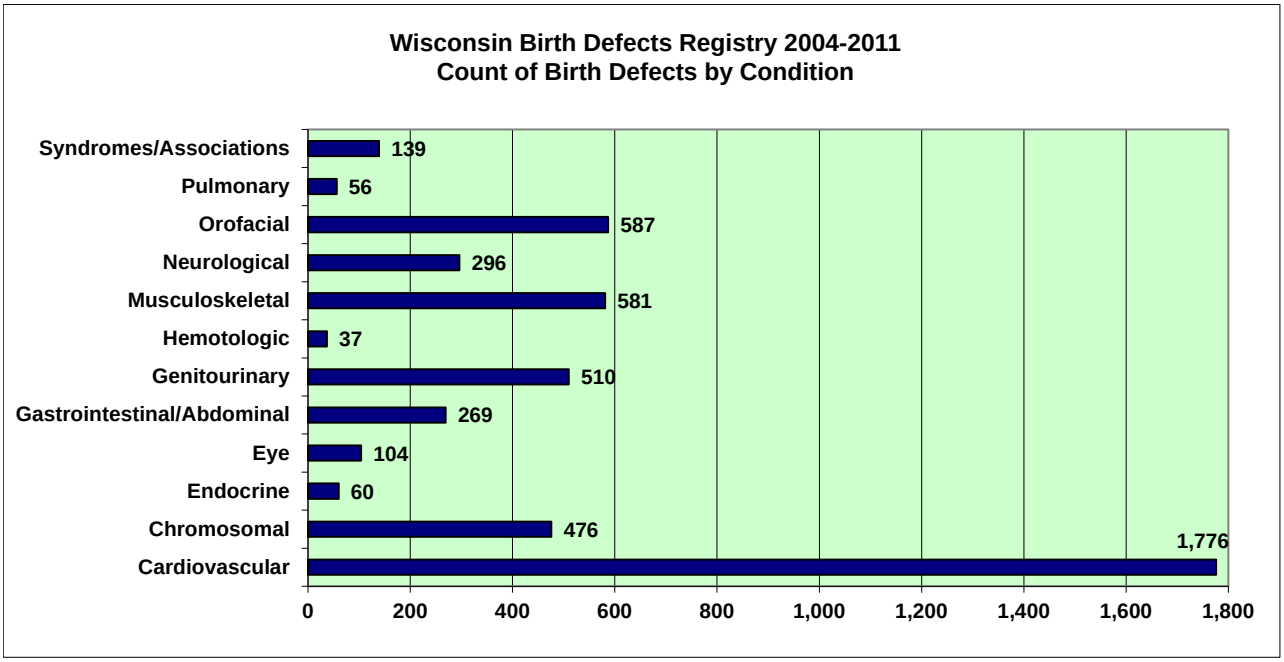
In 2004, a pilot project with Marshfield Clinic developed a process that allows organizations to upload multiple reports from their electronic medical records systems. Ongoing outreach and training opportunities resulted in Dean Health System's move to the electronic upload option in 2011 after all of Dean's clinics migrated to Epic software. They now report for all of their clinics centrally once a month. Children's Hospital of Wisconsin-Milwaukee developed a business protocol for the same method of reporting during 2011 and expects to begin using this protocol in 2012. WBDR staff has consulted with other organizations on the possibility of reporting from their electronic medical records. Experience shows that it takes a minimum of three years for an organization with a new electronic medical records system to discuss the option internally, develop a protocol, implement the protocol, test the upload procedure, and begin regular reporting. The result is more complete reporting on a regular schedule and a more efficient system for the reporter in the long run. (Attachment 1, Confidential Birth Defects Registry Report)

In 2000, $100,000 of state funding for the WBDPSP was provided through General Purpose Revenue (GPR) dollars; however funding was reduced by 10% to $95,000 during the Doyle administration department reductions. The **2009 Wisconsin Act 28 Budget Bill** enacted on June 29, 2009 changed the language of s. 253.12 (7) funding by allocating $95,000 annually from the surcharge on Wisconsin Birth Certificates appropriation account s. 20.435 (1) (gm).

HOW SERIOUS ARE BIRTH DEFECTS IN WISCONSIN?

- Birth defects are common, occurring in 1 out of every 33 births. About 2,000 babies with birth defects are born in Wisconsin every year.
- Birth defects are caused by a variety of different factors: genetic processes, environmental exposures, infections, obesity, as well as the use of alcohol, tobacco, prescription medications, or illegal drugs. Some appear to be multi-factorial with genetic predisposition plus environmental triggers. The causes of about two out of three birth defects are currently unknown.
- Birth defects are the leading cause of all infant deaths and stillbirths, accounting for approximately 150 to 200 deaths in Wisconsin every year.
- Approximately 20% of babies who die in the first year of life do so because of birth defects.
- Babies born with birth defects have a greater chance of illness and long term disability than babies without birth defects.
- Babies with birth defects are often born preterm, which increases the risk of death.
- At least one out of three pediatric hospital admissions is associated with birth defects or genetic conditions.
- The estimated lifetime cost related to birth defects in Wisconsin is estimated at $165 million each year for the 18 most significant birth defects.
- Birth defects are the fifth leading cause of years of potential life lost.

Between mid-2004 and the end of 2011, 4,891 birth defects were reported to the WBDR. The reports show that cardiovascular birth defects are the most common type of condition.



WHAT IS THE PURPOSE OF BIRTH DEFECT SURVEILLANCE?

To prevent birth defects, it is important to know more about what causes them. To identify causes, researchers and analysts need to know the frequency of individual birth defects and they need to compare the occurrence of specific birth defects to the presence of potential causative factors. Ongoing, real-time collection of birth defects is needed to continually assess whether birth defects are increasing, diminishing, or staying the same overall and whether individual birth defects are clustered in a particular geographic area. A core list of birth defects is reported to the National Birth Defect Prevention Network (NBDPN) annually and used to report on national birth defect incidence and trends. CDC cites birth defect surveillance systems as a leading contributor to reducing birth defects. The 2011 report to the NBDPN is included at the end of this report. (Attachment 2)

HOW IS WISCONSIN WORKING TO ADDRESS BIRTH DEFECTS?

Two staff from Title V Children and Youth with Special Health Care Needs (CYSHCN) provide limited support for the program, including registry administration, data analyses, family-support services, and prevention programming.

The CYSHCN epidemiologist administers the WBDR. She is a member of the NBDPN and attends annual training conferences to keep apprised of new information on birth defects. She is also a member of the NBDPN Data Committee and is working with newly developed national prevalence estimates to update Wisconsin's estimated prevalence statistics. A report of the cost of birth defects in Wisconsin is planned to be completed by the end of 2012.

The CYSHCN health promotion consultant manages and administers the WBDPSP budget and agency contracts, oversees the Council on Birth Defect Prevention and Surveillance, is the liaison contact for the Wisconsin March of Dimes and other organizations concerned with birth

defects, and coordinates several birth defect prevention programs and initiatives (i.e., Nourishing Special Needs). She is a member of the NBDPN and is a member of the NBDPN Ethics and Policy Committee working on bylaws and a strategic plan.

Researchers studying birth defects may request and receive summary birth defects registry reports or a dataset with properly executed data release forms and the permission of the state Birth Defects Registry administrator. Projects that WBDR data have supported include: 1) a UW graduate student research project on cleft lip and palate, and 2) ongoing participation with the Bureau of Environmental and Occupational Health in a multi-year Environmental Public Health Tracking Program project funded by the CDC that focuses on tracking birth defects incidence and investigating any relationship between birth defects and environmental hazards.

Birth Defect Prevention and Surveillance Program Outcomes

There are five Regional Centers for Children and Youth with Special Health Care Needs (CYSHCN) in Wisconsin:

1. Northeastern Regional Center for CYSHCN, Children's Hospital of Wisconsin-Fox Valley
2. Northern Regional Center for CYSHCN, Marathon County Health Department
3. Southeastern Regional Center for CYSHCN, Children's Hospital of Wisconsin, Inc.
4. Southern Regional Center for CYSHCN, University of Wisconsin-Waisman Center
5. Western Regional Center for CYSHCN, Chippewa County Department of Public Health

Each Regional Center has designated staff to access birth defect reports from the WBDR for their respective counties and regions. The information is used to assure children with birth defects and their families are contacted and referred to appropriate services.

The WBDPSP currently provides funding to the following prevention and family supports initiatives:

Birth Defects Nutrition Consultant Network (BDNCN)
The BDNCN is a collaborative program improvement initiative developed by the Wisconsin CYSHCN program, the Wisconsin Birth Defects Prevention and Surveillance program, and the Wisconsin Special Supplemental Nutrition Program for Women, Infants and Children (WIC) program to build nutrition services capacity for the identification, intervention, and referral of infants and children (case management) with birth defects seen in WIC.

The BDNCN received state and national attention via presentations at the Wisconsin Public Health Association conference, the Wisconsin Dietetic Association conference, the National Birth Defects Prevention Network conference, the National WIC Association Conference, the National Association of County and City Health Officials conference, and the Association of State and Territorial Public Health Nutrition Directors meeting. In addition, the BDNCN has received many requests from public health agencies throughout the U.S. for copies of the CYSHCN Nutrition Toolkit.

Expansion of the BDNCN, named "Nourishing Special Needs," began in the fall of 2009 and includes a mentor and mentee component (peer nutrition consultation model). The monthly training is open to all WIC Project Sites, the CYSHCN Regional Centers, CYSHCN Hubs of Excellence, Birth to 3 providers, and others who are interested in nutrition issues for children with special needs and children with birth defects.

Evaluation of “Nourishing Special Needs” found that: WIC registered dietitians were frequently the first to identify the need for: 1) initial assessment, diagnosis, and referral for suspected health care problems; 2) additional specialized nutritional assessment and medical nutritional therapy; and 3) special formula or formula changes based on diagnosis.

Baseline data show that the “Nourishing Special Needs” sites currently serve only 15 percent of the Wisconsin statewide WIC client caseload, so expansion to other WIC agencies is essential to help meet access to service needs. Within the state WIC agency caseload, there are an estimated five thousand infants and children with special health care needs, of which 600-700 may have birth defects. In addition, sites demonstrated the following outcomes: 1) a three fold increase in identifying infants and young children with birth defects and other health care needs which accounted for almost half of the referrals to the Wisconsin Regional CYSHCN centers; 2) increased communication and collaboration with other local agencies and medical providers; and 3) improved nutritional care integration with early intervention programs that provided one fifth of the referrals to Wisconsin Birth to 3 program.

As a quality improvement initiative, an integrative model was developed and used to build local nutrition services capacity and to support the Food and Nutrition Services and the National WIC Association Value Enhanced Nutrition Assessment (VENA) counseling strategy to improve quality nutrition services. This model is used for education training at new sites. (Attachment 3, Identification and Intervention for Infants and Children with Special Health Care Needs)

In addition, the state program of the BDNCN provides:

- Training, technical assistance, monthly educational outreach programs and networking teleconferences/”live” meetings and workshop trainings.
- Annual pre-conference training coordination for BCNCN and other attendees at the National WIC Association Conference or State WIC Association conference. This year the conference will focus on the nutrition needs of children with genetic conditions.
- A repository for project data from SPHERE (Secure Public Health Electronic Record Environment) and ROSIE (Real-time Online Statewide Information Environment) computer programs.
- Maintenance of the BDNCN materials on state websites.
- Contract monitoring, oversight, and funding to 13 project sites.
- Participatory educational opportunities for the BDNCN at three Tertiary Neonatal and Pediatric Centers – Birth Defect Medical/Nutrition Specialty Clinics.

Through this quality improvement initiative, the BDNCN developed a system that addresses:

- Communication and facilitation of referrals to primary care, pediatric specialty care, Birth to 3, Wisconsin CYSHCN Regional Centers, economic assistance, and local dietitians providing medical nutritional therapy.
- Collaboration with healthcare providers to ensure documentation for the provision of special infant and pediatric formulas through WIC and for Medicaid reimbursement of nutritional products.
- Training and technical assistance, including the development of a Toolkit and Workbook, and a link to the Wisconsin CSHCN website.
- Data collection and utilization reports for program evaluation.

The Wisconsin Stillbirth Service Program (WiSSP)

The Wisconsin Stillbirth Service Program, located at the Marshfield Clinic Research Foundation, investigates the causes of stillbirth through referrals; provides diagnostic information and educational materials to medical personnel for counseling families with a child who died prior to birth; provides families with other support resources; supplies families and medical personnel with scientific and medical data; and distributes “Grand Rounds” presentation on stillbirth

evaluations to birth centers in Wisconsin. WiSSP submits birth defect reports to the WBDR for any stillbirth in which a reportable condition is diagnosed.
Through a parallel contract objective to ensure statewide availability of bereavement and counseling services, the WiSSP and the Infant Death Center Children's Health Alliance of Wisconsin began collaborating on several similar projects to include opportunities and strategies to form common messaging, promote each other's grief and bereavement materials, and distribute resources statewide.

Wisconsin Pediatric Cardiac Registry
In 2010, the WBDPSP provided funding to the Wisconsin Pediatric Cardiac Registry to support changes to their protocol that would allow reporting of confirmed cardiac defects to the Wisconsin Birth Defects Registry. This project resulted in 519 reports to the WBDR.

Folic Acid Survey Module
Biennially, Wisconsin includes a folic acid survey module in the Behavioral Risk Factor Surveillance System survey. The folic acid module assesses folic acid awareness, communication of the folic acid message, knowledge of folic acid benefits, and consumption of multi-vitamins containing folic acid. The questions are offered only to women of childbearing age. Information from the folic acid module indicates that providing vitamins and education to low-income women is beneficial. Some reproductive health providers have changed their practice of care guidelines to ensure client access to multivitamins with folic acid.

Website
The Children and Youth with Special Health Care Needs Program - Birth Defect Prevention and Surveillance System Website is available at:
http://dhs.wisconsin.gov/health/children/birthdefects/index.htm

SUMMARY

The Wisconsin Birth Defects Prevention and Surveillance program's work focuses on the three core functions of public health: assessment, assurance, and policy development. These core functions are applied in conjunction with the requirements set out in statute: provide an up-to-date birth defects registry that facilitates the identification of risk factors; ensure epidemiology; protect confidentiality; determine reportable birth defects through an Advisory Council; provide for primary prevention to help decrease occurrence; implement components that educate populations about birth defects; and administrate systems that refer those with birth defects to early intervention and other support services.

Endnote

* A major challenge was creating a rational and consistent list of reportable diagnoses. The Birth Defects Advisory Council's Scientific Subcommittee was charged with this task. An initial list was developed based on a set of primary criteria requiring that the proposed birth defect should:
  - Conform to the statutory definition of a birth defect – a structural deformation, disruption or dysplasia, or a genetic, inherited, or biochemical disease that occurs prior to or at birth.
  - Usually be identifiable by two years of age (the limit of the statute).
  - Be a major anomaly (having medical, surgical or developmental significance).
  - Be of 'sufficient' frequency (birth prevalence) – an estimated prevalence of 1/30,000 births was selected; this would mean that two or more occurrences each year in Wisconsin would be expected.

The subcommittee attempted to make the resulting list consistent with data being collected elsewhere in the United States. The list does not include most conditions identified by current newborn bloodspot screening since ascertainment of these is virtually complete. The list was further reviewed by nearly three dozen pediatric sub-specialists (neurology, otolaryngology, hematology, urology, developmental medicine, neurosurgery, neonatology, orthopedic surgery, endocrinology, and cardiology). Their suggestions were analyzed by the Scientific Subcommittee creating the final list written into administrative rules. The list is reviewed annually.

DEPARTMENT OF HEALTH SERVICES
Division of Public Health
DPH 40054 (12/03)

Attachment 1

STATE OF WISCONSIN
Bureau of Family and Community Health

CONFIDENTIAL BIRTH DEFECTS REGISTRY REPORT

Completion of this form by physicians and pediatric specialty clinics is mandated under the provisions of sections 253.12(1) and 253.12 (2) of the Wisconsin Statutes. Completion of this form by hospitals is voluntary. Personally identifiable information collected on this form will only be used for matching and unduplication purposes.

1. Print firmly and neatly
2. Use pen only with dark ink
3. Print inside boxes
4. Fax/mail original form
5. Darken circles completely
6. Mark errors like this: 

A. GENERAL INFORMATION

(1) **Is this report a new report or a correction or addition to a previous report?** O New O Correction

(2) **Has a Parental Consent Form been signed by a parent or guardian?** O Yes O No

(3) **Has a Referral Already Been Made to:**

Regional Children with Special Health Care Needs Center	O Yes	O No
Local Public Health Department	O Yes	O No
Local Birth to 3 Program	O Yes	O No

Other (specify): _____

B. REPORTER

Today's Date (mm/dd/yyyy) / /

Name, Title, Telephone and E-mail Address of Person Completing Form

C. REPORTING SOURCE

Facility Name/Number, Address, City, State and Zip Code (stamp acceptable)

D. CHILD'S INFORMATION

Last Name

Date of Birth (mm/dd/yyyy) / /

First Name

M.I.

Medical Record Number

Street Address

City

State

Zip Code

Sex
O Female
O Male
O Undesignated

Race (check all that apply)
O American Indian or Native Alaskan
O Asian
O Black/African American
O Hawaiian/Pacific Islander
O White
O Other_____
O Unknown

Ethnicity
O Hispanic or Latino
O Not Hispanic or Latino

List other names for child, if any

Birth
O Live
O Stillbirth > 20 weeks gestation

Birthweight
O Grams O Pounds/Ounces
_____

Gestational Age Estimate
Weeks:

Is Birth
O Single OTwin
O Other Multiple_____
O Unknown

Birth Order (if multiple)
O First
O Second
O Other (specify):

Place of Birth: Hospital Name/Code, Street Address, City, State, Zip Code

E. CHILD'S PRIMARY CARE PROVIDER

Name of Primary Care Provider, and Facility Name

Area Code

Telephone Number -

F. CHILD'S MOTHER

Last Name

Date of Birth (mm/dd/yyyy)

First Name

M.I.

Maiden Name

City (at time of birth)

State

Zip Code

Race (check all that apply)

O American Indian or Native Alaskan
O Asian
O Black/African American
O Hawaiian/Pacific Islander
O White
O Other _____
O Unknown

Ethnicity

O Hispanic or Latino
O Not Hispanic or Latino

G. CHILD'S FATHER

Last Name

Date of Birth (mm/dd/yyyy)

First Name

M.I.

Race (check all that apply)

O American Indian or Native Alaskan
O Asian
O Black/African American
O Hawaiian/Pacific Islander
O White
O Other _____
O Unknown

Ethnicity

O Hispanic or Latino
O Not Hispanic or Latino

H. DIAGNOSTIC INFORMATION

Last Name of Physician Making Diagnosis

Date of Diagnosis (mm/dd/yyyy)

First Name

M.I.

License Number

Specialty Area

Area Code

Telephone Number

Condition(s) prenatally diagnosed? O Yes O No O Unknown

Is child deceased? O Yes O No

If child is deceased, date of death (mm/dd/yyyy)

I. WISCONSIN BIRTH DEFECTS REGISTRY REPORTABLE CONDITIONS

Code

Reportable Condition (first 25 letters/spaces)

INSTRUCTIONS

CONFIDENTIAL BIRTH DEFECTS REGISTRY REPORT

(1) This report form is to be used by physicians, pediatric specialty clinics and hospitals to report birth defects for children up to age two. The report is mandated under the provisions of sections 253.12(1) and 253.12(2) of the Wisconsin Statutes. The information is submitted to the Wisconsin Department of Health and Family Services, Bureau of Family and Community Health, Children with Special Health Care Needs Program.
(2) Please fill out as much information as possible. Leave items **blank** if you don't have the information. Do not write "N/A" or similar in the spaces.
(3) This report can be submitted via the Internet. Refer to the website at: https://wbdr.han.wisc.edu for electronic forms and instructions.
(4) If completing the report on paper, fax to Elizabeth Oftedahl, CSHCN Epidemiologist, Bureau of Family and Community Health at 608/267-3824. If sending by U.S. Postal Service mail, her mailing address is 1 W. Wilson Street, P.O. Box 2659, Madison, WI 53701-2659.
(5) Be sure to provide a name, title, telephone number and e-mail address for the person filling out the report so that person can be contacted if there are any questions.
(6) Use the list at the end of this page for section I of the report. If the reportable condition is longer than 25 letters and spaces, put in the proper code number and the first 25 letters and spaces of the reportable condition.
(7) Be sure the parent/guardian has signed a parental consent form (provided and maintained by you or your facility) before submitting the report. If the parent/guardian refuses to sign a consent form, you are still required to report. However, do not provide a name or address for the child or for the child's parents. Do provide date of birth, medical record number (if available), sex, race, ethnicity, birth outcome, birthweight, gestational age estimate, plurality and, if multiple, birth order information.
(8) Contact Elizabeth Oftedahl at 608-261-9304 if you have questions or comments. She can also be reached via e-mail at oftedej@dhfs.state.wi.us

Wisconsin Birth Defects Registry Reportable Conditions

CARDIOVASCULAR
100 Atrial Septal Defect
101 Atrioventricular Canal/Endocardial Cushion Defect
102 Cardiac Arrhythmia (Congenital)
103 Coarctation of the Aorta
104 Hypoplastic Left Heart
105 Tetralogy of Fallot
106 Total Anomalous Pulmonary Venous Return
107 Transposition of the Great Vessels
108 Truncus Arteriosus
109 Valvular Heart Disease (Congenital)
110 Ventricular Septal Defect

CHROMOSOMAL
150 Down Syndrome
151 Klinefelter Syndrome
152 Trisomy 13
153 Trisomy 18
154 Turner Syndrome
155 Velocardiofacial Syndrome (22q Deletion Syndrome)
156 Other Chromosomal Anomaly *(not Down Syndrome, Klinefelter Syndrome, Trisomy 13, Trisomy 18, Turner Syndrome or Velocardiofacial Syndrome)*

ENDOCRINE
200 Hypothyroidism (Congenital)

EYE
250 Cataract (Congenital or Early)
251 Coloboma
252 Glaucoma (Congenital)
253 Microphthalmia/Anophthalmia

GASTROINTESTINAL/ABDOMINAL
300 Biliary Atresia
301 Gastroschisis
302 Hirschsprung Disease
303 Omphalocele
304 Pyloric Stenosis
305 Rectal/Colonic Atresia/Stenosis
306 Small Bowel Atresia/Stenosis
307 Tracheo-Esophageal Fistula/Esophageal Atresia

GENITOURINARY
350 Ambiguous Genitalia
351 Epispadias
352 Exstrophy of the Bladder/Cloaca
353 Hypospadias
354 Multicystic and/or Dysplastic Kidney
355 Obstructive Urinary Tract Defect *(not Posterior Valves; not Urethral Stenosis/Atresia)*
356 Polycystic Kidney Disease, Autosomal Dominant Form
357 Polycystic Kidney Disease, Autosomal Recessive Form
358 Polycystic Kidney Disease, Uncertain Form
359 Posterior Urethral Valves
360 Renal Agenesis/Hypoplasia
361 Urethral Stenosis/Atresia

HEMATOLOGIC
400 Hemophilia
401 Hereditary Spherocytosis
402 Von Willebrand Disease

MUSCULOSKELETAL
450 Achondroplasia
451 Amniotic Bands
452 Arthrogryposis Multiplex Congenita
453 Bone Dysplasia/Dwarfism, Other *(not Anchondroplasia)*
454 Clubfoot (Congenital)
455 Hip Dislocation (Congenital)/Developmental Dysplasia of Hip (Congenital)
456 Hemivertebra
457 Osteogenesis Imperfecta
458 Scoliosis (Infantile) and/or Kyphosis
459 Reduction Deformity, Arm or Hand
460 Reduction Deformity, Leg or Foot

NEUROLOGIC
500 Anencephaly
501 Encephalocele
502 Holoprosencephaly
503 Hydranencephaly
504 Hydrocephalus (Congenital or Early)
505 Microcephaly (Congenital or Early)
506 Porencephaly
507 Spina Bifida
508 Spinal Muscular Atrophy (Infantile)

OROFACIAL
550 Choanal Atresia
551 Cleft Lip with or without Cleft Palate
552 Cleft Palate
553 Craniosynostosis
554 Microtia/Anotia

PULMONARY
600 Cystic Fibrosis
601 Diaphragmatic Hernia

SYNDROMES/ASSOCIATIONS
650 Angelman Syndrome
651 Beckwith-Wiedemann Syndrome
652 CHARGE Association
653 De Lange Syndrome (Cornelia De Lange Syndrome)
654 Marfan Syndrome
655 Noonan Syndrome
656 Oculoauriculovertebral Association *(including Goldenhar Association and Hemifacial Microsomia)*
657 Prader-Willi Syndrome
658 Robin Malformation Sequence (Pierre Robin Sequence)
659 Smith-Lemli-Opitz Syndrome
660 Sotos Syndrome
661 Stickler Syndrome
662 VATER Association
663 Williams Syndrome

Data submission (5 worksheets):
When generating your data tables, please use the column and row order listed in tables 1, 1a, 2, 2b as well as the defect codes and the column name codes (caps, bold). For defects without any cases, put "0" in the tables; a blank cell implies unavailable data.
Table 1:Data for 45 Birth Defects by Race for 2004-2008. Please complete this table for each birth year requested.
Table 1a: Table for total live births by race
Table 2: Data for trisomies by age for 2004-2008. Please complete this table for each birth year requested.
Table 2a: Table for total live births by age

Table 1: Data for 45 Birth Defects by Race for 2004, 2005, 2006, 2007, 2008

Defect to be reported	Defect Code	Non-Hispanic White	Non-Hispanic Black or African-American	Hispanic	Non-Hispanic Asian or Pacific Islander	Non-Hispanic American Indian or Alaska Native	Other/ Unknown	Total	Comments for individual defect
Anencephalus - **Total**	1	40	5	8	3	0	2	58	
Anencephalus - Livebirths	1	18	4	6	1	0	1	30	
Anencephalus - Stillbirths	1	22	1	2	2	0	1	28	Fetal deaths >= 20 weeks
Anencephalus - Terminations	1	N/A	N/A	N/A	N/A	N/A	N/A	N/A	No data available
Spina bifida without anencephalus - **Total**	2	81	8	7	1	1	0	98	
Spina bifida without anencephalus - Livebirths	2	81	8	7	1	1	0	98	
Spina bifida without anencephalus - Stillbirths	2	0	0	0	0	0	0	0	Fetal deaths >= 20 weeks
Spina bifida without anencephalus - Terminations	2	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Please give the gestational age cut off you use for terminations.
Hydrocephalus without Spina Bifida	3	66	19	15	2	2	0	104	
Encephalocele	4	10	3	1	1	1	0	16	
Microcephalus	5	32	9	4	2	0	0	47	
Anophthalmia/microphthalmia	6	14	6	2	1	0	0	23	
Congenital cataract	7	23	4	2	0	0	0	29	
Aniridia	8	3	3	0	0	0	0	6	
Anotia/microtia	9	18	1	8	0	0	0	27	
Common truncus	10	13	2	5	0	0	0	20	
Transposition of great arteries	11	40	4	10	1	3	0	58	
Tetralogy of Fallot	12	49	11	8	2	1	0	71	

2004, 2005, 2006, 2007, 2008 Defect to be reported	Defect Code	Non-Hispanic White	Non-Hispanic Black or African-American	Hispanic	Non-Hispanic Asian or Pacific Islander	Non-Hispanic American Indian or Alaska Native	Other/ Unknown	Total	Comments for individual defect
Ventricular septal defect	14	632	58	105	35	24	0	854	Hospital practice in coding is not known.
Atrial septal defect	15	838	127	105	33	45	0	1148	
Atrioventricular septal defect, AVSD (endocardial cushion defect)	16	44	6	2	1	1	0	54	
Pulmonary valve atresia and stenosis	17	68	17	12	6	3	0	106	
Tricuspid valve atresia and stenosis	18	14	4	1	1	0	0	20	
Ebstein's anomaly	19	7	0	2	1	0	0	10	
Aortic valve stenosis	20	19	0	1	1	1	0	22	
Hypoplastic left heart syndrome	21	38	10	3	2	1	0	54	
Patent ductus arteriosus	22	703	106	101	29	27	0	966	Include only if weight =>2500 grams, please note if you are unable to exclude <2500 grams infants.
Coarctation of aorta	23	41	4	6	1	1	0	53	
Cleft palate w/out cleft lip	26	167	14	10	6	4	1	202	
Cleft lip with and without cleft palate	27	249	27	35	4	11	0	326	
Choanal atresia	28	27	1	8	0	0	0	36	
Esophageal atresia/ tracheoesophageal fistula	29	60	7	4	2	0	0	73	
Rectal and large intestinal atresia/stenosis	30	88	8	9	4	2	0	111	
Pyloric stenosis	31	4	0	0	0	0	0	4	
Hirshsprung's disease (congenital megacolon)	32	14	3	3	2	0	0	22	
Biliary atresia	33	1	0	0	0	1	0	2	
Renal agenesis/hypoplasia	34	72	5	12	5	2	0	96	
Bladder exstrophy	35	11	0	0	0	0	0	11	
Obstructive genitourinary defect	36	485	42	39	24	16	0	606	
Hypospadias	50	978	114	53	14	10	2	1171	

2004, 2005, 2006, 2007, 2008 Defect to be reported	Defect Code	Non-Hispanic White	Non-Hispanic Black or African-American	Hispanic	Non-Hispanic Asian or Pacific Islander	Non-Hispanic American Indian or Alaska Native	Other/ Unknown	Total	Comments for individual defect
Epispadias	51	24	4	3	1	0	0	32	
Reduction deformity, upper limbs	38	66	9	8	3	4	0	90	
Reduction deformity, lower limbs	39	27	3	3	1	1	0	35	
Gastroschisis	40	158	25	25	12	10	0	230	Cannot distinguish between the two.
Omphalocele	41	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Congenital hip dislocation	42	185	7	22	6	0	0	220	
Diaphragmatic hernia	43	44	11	10	0	1	0	66	
Trisomy 13 (Patau syndrome) - **Total**	44	19	2	4	2	0	0	27	
Trisomy 13 - Livebirths	44	19	2	4	2	0	0	27	
Trisomy 13 - Stillbirths	44	0	0	0	0	0	0	0	
Trisomy 13 - Terminations	44	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Trisomy 21 (Down syndrome) **Total**	45	331	22	57	24	6	0	440	
Trisomy 21 - Livebirths	45	330	22	57	24	6	0	439	
Trisomy 21 - Stillbirths	45	1	0	0	0	0	0	1	
Trisomy 21 - Terminations	45	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Trisomy 18 (Edwards syndrome) **Total**	46	56	10	7	1	0	1	75	
Trisomy 18 - Livebirths	46	27	7	5	1	0	0	40	
Trisomy 18 - Stillbirths	46	29	3	2	0	0	1	35	
Trisomy 18 - Terminations	46	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Fetus or newborn affected by maternal alcohol use	47	18	10	3	0	3	0	34	
Amniotic bands	48	N/A	N/A	N/A	N/A	N/A	N/A	N/A	No Code

For Year 2004 Only

Defect to be reported	Defect Code	Non-Hispanic White	Non-Hispanic Black or African-American	Hispanic	Non-Hispanic Asian or Pacific Islander	Non-Hispanic American Indian or Alaska Native	Other/ Unknown	Total	Comments for individual defect
Anencephalus - **Total**	1	6	0	1	0	0	0	7	
Anencephalus - Livebirths	1	4	0	1	0	0	0	5	
Anencephalus - Stillbirths	1	2	0	0	0	0	0	2	Fetal Deaths >=20 weeks
Anencephalus - Terminations	1	N/A	N/A	N/A	N/A	N/A	N/A	N/A	No data available
Spina bifida without anencephalus - **Total**	2	15	1	1	0	0	0	17	
Spina bifida without anencephalus - Livebirths	2	15	1	1	0	0	0	17	
Spina bifida without anencephalus - Stillbirths	2	0	0	0	0	0	0	0	Fetal Deaths >=20 weeks
Spina bifida without anencephalus - Terminations	2	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Please give the gestational age cut off you use for terminations.
Hydrocephalus without Spina Bifida	3	14	4	4	0	2	0	24	
Encephalocele	4	1	1	1	0	0	0	3	
Microcephalus	5	9	2	1	0	0	0	12	
Anophthalmia/ microphthalmia	6	1	1	1	0	0	0	3	
Congenital cataract	7	3	0	1	0	0	0	4	
Aniridia	8	1	0	0	0	0	0	1	
Anotia/microtia	9	4	0	0	0	0	0	4	
Common truncus	10	1	0	2	0	0	0	3	
Transposition of great arteries	11	5	0	1	0	2	0	8	
Tetralogy of Fallot	12	11	2	1	1	0	0	15	
Ventricular septal defect	14	140	12	11	6	6	0	175	Hospital practice in coding is not known.
Atrial septal defect	15	121	26	10	5	10	0	172	
Atrioventricular septal defect, AVSD (endocardial cushion defect)	16	4	1	0	0	1	0	6	
Pulmonary valve atresia and stenosis	17	6	2	2	1	0	0	11	

2004 Only Defect to be reported	Defect Code	Non-Hispanic White	Non-Hispanic Black or African-American	Hispanic	Non-Hispanic Asian or Pacific Islander	Non-Hispanic American Indian or Alaska Native	Other/ Unknown	Total	Comments for individual defect
Tricuspid valve atresia and stenosis	18	0	0	0	0	0	0	0	
Ebstein's anomaly	19	2	0	0	1	0	0	3	
Aortic valve stenosis	20	4	0	0	0	0	0	4	
Hypoplastic left heart syndrome	21	5	1	0	0	1	0	7	
Patent ductus arteriosus	22	124	17	13	6	8	0	168	Include only if weight =>2500 grams, please note if you are unable to exclude <2500 grams infants.
Coarctation of aorta	23	9	0	1	0	1	0	11	
Cleft palate without cleft lip	26	39	3	1	0	1	0	44	
Cleft lip with w/out cleft palate	27	59	4	7	0	3	0	73	
Choanal atresia	28	4	0	4	0	0	0	8	
Esophageal atresia/ tracheoesophageal fistula	29	12	2	1	0	0	0	15	
Rectal and large intestinal atresia/stenosis	30	16	4	2	1	1	0	24	
Pyloric stenosis	31	1	0	0	0	0	0	1	
Hirshsprung's disease (congenital megacolon)	32	6	0	1	0	0	0	7	
Biliary atresia	33	0	0	0	0	0	0	0	
Renal agenesis/hypoplasia	34	9	3	3	0	1	0	16	
Bladder exstrophy	35	4	0	0	0	0	0	4	
Obstructive genitourinary defect	36	97	9	8	3	3	0	120	
Hypospadias	50	201	21	6	3	1	0	232	
Epispadias	51	5	0	1	0	0	0	6	
Reduction deformity, upper limbs	38	18	3	1	0	2	0	24	
Reduction deformity, lower limbs	39	4	1	0	0	1	0	6	
Gastroschisis	40	21	6	1	1	1	0	30	Cannot distinguish the two defects
Omphalocele	41	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Congenital hip dislocation	42	35	3	4	2	0	0	44	
Diaphragmatic hernia	43	11	4	2	0	0	0	17	
Trisomy 13 (Patau syndrome) - **Total**	44	1	0	1	1	0	0	3	

2004 Only Defect to be reported	Defect Code	Non-Hispanic White	Non-Hispanic Black or African-American	Hispanic	Non-Hispanic Asian or Pacific Islander	Non-Hispanic American Indian or Alaska Native	Other/ Unknown	Total	Comments for individual defect
Trisomy 13 - Livebirths	44	1	0	1	1	0	0	3	
Trisomy 13 - Stillbirths	44	0	0	0	0	0	0	0	
Trisomy 13 - Terminations	44	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Trisomy 21 (Down syndrome) **Total**	45	72	0	9	2	2	0	85	
Trisomy 21 - Livebirths	45	71	0	9	2	2	0	84	
Trisomy 21 - Stillbirths	45	1	0	0	0	0	0	1	
Trisomy 21 - Terminations	45	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Trisomy 18 (Edwards syndrome) **Total**	46	10	3	0	0	0	0	13	
Trisomy 18 - Livebirths	46	6	1	0	0	0	0	7	
Trisomy 18 - Stillbirths	46	4	2	0	0	0	0	6	
Trisomy 18 - Terminations	46	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Fetus or newborn affected by maternal alcohol use	47	2	3	0	0	0	0	5	
Amniotic bands	48	N/A	N/A	N/A	N/A	N/A	N/A	N/A	No Code

For Year 2005 Only

Defect to be reported	Defect Code	Non-Hispanic White	Non-Hispanic Black or African-American	Hispanic	Non-Hispanic Asian or Pacific Islander	Non-Hispanic American Indian or Alaska Native	Other/ Unknown	Total	Comments for individual defect
Anencephalus - **Total**	1	10	1	2	0	0	2	15	
Anencephalus - Livebirths	1	5	1	1	0	0	1	8	
Anencephalus - Stillbirths	1	5	0	1	0	0	1	7	Fetal Deaths >=20 weeks
Anencephalus - Terminations	1	N/A	N/A	N/A	N/A	N/A	N/A	N/A	No data available
Spina bifida without anencephalus - **Total**	2	14	2	0	0	0	0	16	
Spina bifida without anencephalus - Livebirths	2	14	2	0	0	0	0	16	
Spina bifida without anencephalus - Stillbirths	2	0	0	0	0	0	0	0	Fetal Deaths >=20 weeks
Spina bifida without anencephalus - Terminations	2	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Please give gestational age cut off used for terminations.
Hydrocephalus without Spina Bifida	3	9	4	1	1	0	0	15	

2005 Only Defect to be reported	Defect Code	Non-Hispanic White	Non-Hispanic Black or African-American	Hispanic	Non-Hispanic Asian or Pacific Islander	Non-Hispanic American Indian or Alaska Native	Other/ Unknown	Total	Comments for individual defect
Encephalocele	4	2	1	0	0	1	0	4	
Microcephalus	5	7	2	1	0	0	0	10	
Anophthalmia/ microphthalmia	6	3	1	0	1	0	0	5	
Congenital cataract	7	6	0	0	0	0	0	6	
Aniridia	8	0	0	0	0	0	0	0	
Anotia/microtia	9	5	0	1	0	0	0	6	
Common truncus	10	2	1	2	0	0	0	5	
Transposition of great arteries	11	7	1	2	1	0	0	11	
Tetralogy of Fallot	12	8	0	3	1	0	0	12	
Ventricular septal defect	14	125	12	15	9	5	0	166	Hospital practice in coding is not known.
Atrial septal defect	15	144	34	18	6	6	0	208	
Atrioventricular septal defect, AVSD (endocardial cushion defect)	16	10	0	1	0	0	0	11	
Pulmonary valve atresia and stenosis	17	19	5	2	1	0	0	27	
Tricuspid valve atresia and stenosis	18	2	1	0	0	0	0	3	
Ebstein's anomaly	19	2	0	0	0	0	0	2	
Aortic valve stenosis	20	5	0	0	1	0	0	6	
Hypoplastic left heart syndrome	21	9	3	1	2	0	0	15	
Patent ductus arteriosus	22	136	18	10	4	3	0	171	Include only if weight =>2500 grams, please note if you are unable to exclude <2500 grams infants.
Coarctation of aorta	23	10	0	1	1	0	0	12	
Cleft palate without cleft lip	26	30	1	3	2	1	0	37	
Cleft lip with and without cleft palate	27	48	3	8	1	0	0	60	
Choanal atresia	28	7	1	1	0	0	0	9	
Esophageal atresia/ tracheoesophageal fistula	29	13	0	1	1	0	0	15	
Rectal and large intestinal atresia/stenosis	30	18	0	0	0	0	0	18	
Pyloric stenosis	31	0	0	0	0	0	0	0	
Hirshsprung's disease (congenital megacolon)	32	1	1	0	0	0	0	2	

2005 Only Defect to be reported	Defect Code	Non-Hispanic White	Non-Hispanic Black or African-American	Hispanic	Non-Hispanic Asian or Pacific Islander	Non-Hispanic American Indian or Alaska Native	Other/ Unknown	Total	Comments for individual defect
Biliary atresia	33	0	0	0	0	1	0	1	
Renal agenesis/hypoplasia	34	13	0	4	3	0	0	20	
Bladder exstrophy	35	1	0	0	0	0	0	1	
Obstructive genitourinary defect	36	97	8	7	6	2	0	120	
Hypospadias	50	187	19	9	2	2	1	220	
Epispadias	51	6	1	1	0	0	0	8	
Reduction deformity, upper limbs	38	15	0	2	1	1	0	19	
Reduction deformity, lower limbs	39	5	0	1	0	0	0	6	
Gastroschisis	40	30	5	5	2	2	0	44	Cannot distinguish
Omphalocele	41	N/A	N/A	N/A	N/A	N/A	N/A	N/A	between these two
Congential hip dislocation	42	41	0	3	2	0	0	46	
Diaphragmatic hernia	43	9	2	2	0	0	0	13	
Trisomy 13 (Patau syndrome) - **Total**	44	3	1	0	1	0	0	5	
Trisomy 13 - Livebirths	44	3	1	0	1	0	0	5	
Trisomy 13 - Stillbirths	44	0	0	0	0	0	0	0	
Trisomy 13 - Terminations	44	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Trisomy 21 (Down syndrome) **Total**	45	56	7	6	3	1	0	73	
Trisomy 21 - Livebirths	45	56	7	6	3	1	0	73	
Trisomy 21 - Stillbirths	45	0	0	0	0	0	0	0	
Trisomy 21 - Terminations	45	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Trisomy 18 (Edwards syndrome) **Total**	46	16	1	2	0	0	0	19	
Trisomy 18 - Livebirths	46	5	1	1	0	0	0	7	
Trisomy 18 - Stillbirths	46	11	0	1	0	0	0	12	
Trisomy 18 - Terminations	46	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Fetus or newborn affected by maternal alcohol use	47	2	2	1	0	1	0	6	
Amniotic bands	48	N/A	N/A	N/A	N/A	N/A	N/A	N/A	No Code

For Year 2006 Only

Defect to be reported	Defect Code	Non-Hispanic White	Non-Hispanic Black or African-American	Hispanic	Non-Hispanic Asian or Pacific Islander	Non-Hispanic American Indian or Alaska Native	Other/ Unknown	Total	Comments for individual defect
Anencephalus - **Total**	1	7	2	1	1	0	0	11	
Anencephalus - Livebirths	1	3	2	1	1	0	0	7	
Anencephalus - Stillbirths	1	4	0	0	0	0	0	4	Fetal Deaths >=20 weeks
Anencephalus - Terminations	1	N/A	N/A	N/A	N/A	N/A	N/A	N/A	No data available
Spina bifida without anencephalus - **Total**	2	9	1	3	0	0	0	13	
Spina bifida without anencephalus - Livebirths	2	9	1	3	0	0	0	13	
Spina bifida without anencephalus - Stillbirths	2	0	0	0	0	0	0	0	Fetal Deaths >=20 weeks
Spina bifida without anencephalus - Terminations	2	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Please give the gestational age cut off you use for terminations.
Hydrocephalus without Spina Bifida	3	13	1	6	0	0	0	20	
Encephalocele	4	2	1	0	1	0	0	4	
Microcephalus	5	5	3	1	0	0	0	9	
Anophthalmia/ microphthalmia	6	4	2	0	0	0	0	6	
Congenital cataract	7	4	2	0	0	0	0	6	
Aniridia	8	1	0	0	0	0	0	1	
Anotia/microtia	9	4	0	1	0	0	0	5	
Common truncus	10	2	0	0	0	0	0	2	
Transposition of great arteries	11	8	1	2	0	1	0	12	
Tetralogy of Fallot	12	11	1	0	0	0	0	12	
Ventricular septal defect	14	120	10	28	5	7	0	170	Hospital practice in coding is not known.
Atrial septal defect	15	181	28	22	8	7	0	246	
Atrioventricular septal defect, AVSD (endocardial cushion defect)	16	8	2	1	0	0	0	11	
Pulmonary valve atresia and stenosis	17	14	4	0	0	0	0	18	
Tricuspid valve atresia and stenosis	18	3	3	0	0	0	0	6	
Ebstein's anomaly	19	0	0	0	0	0	0	0	
Aortic valve stenosis	20	5	0	1	0	0	0	6	
Hypoplastic left heart syndrome	21	5	0	0	0	0	0	5	

2006 Only Defect to be reported	Defect Code	Non-Hispanic White	Non-Hispanic Black or African-American	Hispanic	Non-Hispanic Asian or Pacific Islander	Non-Hispanic American Indian or Alaska Native	Other/ Unknown	Total	Comments for individual defect
Patent ductus arteriosus	22	154	19	27	9	1	0	210	Include only if weight =>2500 grams, please note if you are unable to exclude <2500 grams infants.
Coarctation of aorta	23	4	2	0	0	0	0	6	
Cleft palate without cleft lip	26	30	2	2	2	1	0	37	
Cleft lip with and without cleft palate	27	53	8	7	0	4	0	72	
Choanal atresia	28	4	0	2	0	0	0	6	
Esophageal atresia/ tracheoesophageal fistula	29	11	4	1	1	0	0	17	
Rectal and large intestinal atresia/stenosis	30	17	2	1	0	1	0	21	
Pyloric stenosis	31	2	0	0	0	0	0	2	
Hirshsprung's disease (congenital megacolon)	32	0	2	1	0	0	0	3	
Biliary atresia	33	1	0	0	0	0	0	1	
Renal agenesis/hypoplasia	34	17	1	0	1	1	0	20	
Bladder exstrophy	35	2	0	0	0	0	0	2	
Obstructive genitourinary defect	36	109	14	6	7	6	0	142	
Hypospadias	50	216	20	8	5	2	1	252	
Epispadias	51	3	1	0	0	0	0	4	
Reduction deformity, upper limbs	38	13	2	1	0	0	0	16	
Reduction deformity, lower limbs	39	7	2	0	0	0	0	9	
Gastroschisis	40	41	7	7	0	2	0	57	Cannot distinguish between two conditions
Omphalocele	41	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Congential hip dislocation	42	38	1	5	1	0	0	45	
Diaphragmatic hernia	43	5	1	1	0	0	0	7	
Trisomy 13 (Patau syndrome) - **Total**	44	5	0	1	0	0	0	6	
Trisomy 13 - Livebirths	44	5	0	1	0	0	0	6	
Trisomy 13 - Stillbirths	44	0	0	0	0	0	0	0	
Trisomy 13 - Terminations	44	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Trisomy 21 (Down syndrome) **Total**	45	65	3	12	4	2	0	86	
Trisomy 21 - Livebirths	45	65	3	12	4	2	0	86	
Trisomy 21 - Stillbirths	45	0	0	0	0	0	0	0	
Trisomy 21 - Terminations	45	N/A	N/A	N/A	N/A	N/A	N/A	N/A	

2006 Only Defect to be reported	Defect Code	Non-Hispanic White	Non-Hispanic Black or African-American	Hispanic	Non-Hispanic Asian or Pacific Islander	Non-Hispanic American Indian or Alaska Native	Other/ Unknown	Total	Comments for individual defect
Trisomy 18 (Edwards syndrome) **Total**	46	13	1	2	0	0	1	17	
Trisomy 18 - Livebirths	46	11	0	1	0	0	0	12	
Trisomy 18 - Stillbirths	46	2	1	1	0	0	1	5	
Trisomy 18 - Terminations	46	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Fetus or newborn affected by maternal alcohol use	47	8	2	1	0	0	0	11	
Amniotic bands	48	N/A	N/A	N/A	N/A	N/A	N/A	N/A	No Code

For Year 2007 Only

Defect to be reported	Defect Code	Non-Hispanic White	Non-Hispanic Black or African-American	Hispanic	Non-Hispanic Asian or Pacific Islander	Non-Hispanic American Indian or Alaska Native	Other/ Unknown	Total	Comments for individual defect
Anencephalus - **Total**	1	4	1	3	0	0	0	8	
Anencephalus - Livebirths	1	2	0	2	0	0	0	4	
Anencephalus - Stillbirths	1	2	1	1	0	0	0	4	Fetal Deaths >=20 weeks
Anencephalus - Terminations	1	N/A	N/A	N/A	N/A	N/A	N/A	N/A	No data available
Spina bifida without anencephalus - **Total**	2	23	2	2	0	1	0	28	
Spina bifida without anencephalus - Livebirths	2	23	2	2	0	1	0	28	
Spina bifida without anencephalus - Stillbirths	2	0	0	0	0	0	0	0	Fetal Deaths >=20 weeks
Spina bifida without anencephalus - Terminations	2	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Please give the gestational age cut off you use for terminations.
Hydrocephalus without Spina Bifida	3	14	4	3	1	0	0	22	
Encephalocele	4	3	0	0	0	0	0	3	
Microcephalus	5	6	2	0	0	0	0	8	
Anophthalmia/ microphthalmia	6	3	1	1	0	0	0	5	
Congenital cataract	7	2	1	0	0	0	0	3	
Aniridia	8	0	1	0	0	0	0	1	
Anotia/microtia	9	3	0	4	0	0	0	7	
Common truncus	10	4	0	0	0	0	0	4	
Transposition of great arteries	11	10	1	1	0	0	0	12	

2007 Only Defect to be reported	Defect Code	Non-Hispanic White	Non-Hispanic Black or African-American	Hispanic	Non-Hispanic Asian or Pacific Islander	Non-Hispanic American Indian or Alaska Native	Other/ Unknown	Total	Comments for individual defect
Tetralogy of Fallot	12	12	4	3	0	0	0	19	
Ventricular septal defect	14	128	15	20	5	3	0	171	Hospital practice in coding is not known.
Atrial septal defect	15	180	19	21	7	10	0	237	
Atrioventricular septal defect, AVSD (endocardial cushion defect)	16	15	3	0	0	0	0	18	
Pulmonary valve atresia and stenosis	17	17	4	3	2	0	0	26	
Tricuspid valve atresia and stenosis	18	3	0	0	0	0	0	3	
Ebstein's anomaly	19	0	0	0	0	0	0	0	
Aortic valve stenosis	20	4	0	0	0	0	0	4	
Hypoplastic left heart syndrome	21	12	3	1	0	0	0	16	
Patent ductus arteriosus	22	149	30	25	4	11	0	219	Include only if weight =>2500 grams, please note if you are unable to exclude <2500 grams infants.
Coarctation of aorta	23	5	1	0	0	0	0	6	
Cleft palate without cleft lip	26	28	6	2	0	1	1	38	
Cleft lip with and without cleft palate	27	46	8	7	3	3	0	67	
Choanal atresia	28	7	0	1	0	0	0	8	
Esophageal atresia/ tracheoesophageal fistula	29	14	0	0	0	0	0	14	
Rectal and large intestinal atresia/stenosis	30	22	1	5	2	0	0	30	
Pyloric stenosis	31	0	0	0	0	0	0	0	
Hirshsprung's disease (congenital megacolon)	32	4	0	0	0	0	0	4	
Biliary atresia	33	0	0	0	0	0	0	0	
Renal agenesis/hypoplasia	34	15	1	2	0	0	0	18	
Bladder exstrophy	35	3	0	0	0	0	0	3	
Obstructive genitourinary defect	36	90	7	12	6	3	0	118	
Hypospadias	50	185	20	12	2	3	0	222	
Epispadias	51	4	0	0	0	0	0	4	
Reduction deformity, upper limbs	38	10	3	2	1	0	0	16	
Reduction deformity, lower limbs	39	2	0	1	0	0	0	3	

2007 Only Defect to be reported	Defect Code	Non-Hispanic White	Non-Hispanic Black or African-American	Hispanic	Non-Hispanic Asian or Pacific Islander	Non-Hispanic American Indian or Alaska Native	Other/ Unknown	Total	Comments for individual defect
Gastroschisis	40	34	4	5	5	2	0	50	Cannot distinguish between the two defects
Omphalocele	41	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Congential hip dislocation	42	38	2	5	0	0	0	45	
Diaphragmatic hernia	43	10	2	3	0	1	0	16	
Trisomy 13 (Patau syndrome) - **Total**	44	3	1	1	0	0	0	5	
Trisomy 13 - Livebirths	44	3	1	1	0	0	0	5	
Trisomy 13 - Stillbirths	44	0	0	0	0	0	0	0	
Trisomy 13 - Terminations	44	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Trisomy 21 (Down syndrome) **Total**	45	81	8	17	1	0	0	107	
Trisomy 21 - Livebirths	45	81	8	17	1	0	0	107	
Trisomy 21 - Stillbirths	45	0	0	0	0	0	0	0	
Trisomy 21 - Terminations	45	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Trisomy 18 (Edwards syndrome) **Total**	46	8	3	2	0	0	0	13	
Trisomy 18 - Livebirths	46	4	3	2	0	0	0	9	
Trisomy 18 - Stillbirths	46	4	0	0	0	0	0	4	
Trisomy 18 - Terminations	46	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Fetus or newborn affected by maternal alcohol use	47	2	2	0	0	1	0	5	
Amniotic bands	48	N/A	N/A	N/A	N/A	N/A	N/A	N/A	No Code

For Year 2008 Only

Defect to be reported	Defect Code	Non-Hispanic White	Non-Hispanic Black or African-American	Hispanic	Non-Hispanic Asian or Pacific Islander	Non-Hispanic American Indian or Alaska Native	Other/ Unknown	Total	Comments for individual defect
Anencephalus - **Total**	1	12	1	1	2	0	0	17	
Anencephalus - Livebirths	1	4	1	1	0	0	0	6	
Anencephalus - Stillbirths	1	8	0	0	2	0	0	11	Fetal Deaths >=20 weeks
Anencephalus - Terminations	1	N/A	N/A	N/A	N/A	N/A	N/A	N/A	No data available
Spina bifida without anencephalus - **Total**	2	20	2	1	1	0	0	24	
Spina bifida without anencephalus - Livebirths	2	20	2	1	1	0	0	24	

2008 Only Defect to be reported	Defect Code	Non-Hispanic White	Non-Hispanic Black or African-American	Hispanic	Non-Hispanic Asian or Pacific Islander	Non-Hispanic American Indian or Alaska Native	Other/ Unknown	Total	Comments for individual defect
Spina bifida without anencephalus - Stillbirths	2	0	0	0	0	0	0	0	Fetal Deaths >=20 weeks
Spina bifida without anencephalus - Terminations	2	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Please give the gestational age cut off you use for terminations.
Hydrocephalus without Spina Bifida	3	16	6	1	0	0	0	23	
Encephalocele	4	2	0	0	0	0	0	2	
Microcephalus	5	5	0	1	2	0	0	8	
Anophthalmia/ microphthalmia	6	3	1	0	0	0	0	4	
Congenital cataract	7	8	1	1	0	0	0	10	
Aniridia	8	1	2	0	0	0	0	3	
Anotia/microtia	9	2	1	2	0	0	0	5	
Common truncus	10	4	1	1	0	0	0	6	
Transposition of great arteries	11	10	1	4	0	0	0	15	
Tetralogy of Fallot	12	7	4	1	0	1	0	13	
Ventricular septal defect	14	119	9	31	10	3	0	172	Hospital practice in coding is not known.
Atrial septal defect	15	212	20	34	7	12	0	285	
Atrioventricular septal defect, AVSD (endocardial cushion defect)	16	7	0	0	1	0	0	8	
Pulmonary valve atresia and stenosis	17	12	2	5	2	3	0	24	
Tricuspid valve atresia and stenosis	18	6	0	1	1	0	0	8	
Ebstein's anomaly	19	3	0	2	0	0	0	5	
Aortic valve stenosis	20	1	0	0	0	1	0	2	
Hypoplastic left heart syndrome	21	7	3	1	0	0	0	11	
Patent ductus arteriosus	22	140	22	26	6	4	0	198	Include only if weight =>2500 grams, please note if you are unable to exclude <2500 grams infants.
Coarctation of aorta	23	13	1	4	0	0	0	18	
Cleft palate without cleft lip	26	40	2	2	2	0	0	46	
Cleft lip with and without cleft palate	27	43	4	6	0	1	0	54	
Choanal atresia	28	5	0	0	0	0	0	5	

2008 Only Defect to be reported	Defect Code	Non-Hispanic White	Non-Hispanic Black or African-American	Hispanic	Non-Hispanic Asian or Pacific Islander	Non-Hispanic American Indian or Alaska Native	Other/ Unknown	Total	Comments for individual defect
Esophageal atresia/ tracheoesophageal fistula	29	10	1	1	0	0	0	12	
Rectal and large intestinal atresia/stenosis	30	15	1	1	1	0	0	18	
Pyloric stenosis	31	1	0	0	0	0	0	1	
Hirshsprung's disease (congenital megacolon)	32	3	0	1	2	0	0	6	
Biliary atresia	33	0	0	0	0	0	0	0	
Renal agenesis/hypoplasia	34	18	0	3	1	0	0	22	
Bladder exstrophy	35	1	0	0	0	0	0	1	
Obstructive genitourinary defect	36	92	4	6	2	2	0	106	
Hypospadias	50	189	34	18	2	2	0	245	
Epispadias	51	6	2	1	1	0	0	10	
Reduction deformity, upper limbs	38	10	1	2	1	1	0	15	
Reduction deformity, lower limbs	39	9	0	1	1	0	0	11	
Gastroschisis	40	32	3	7	4	3	0	49	Cannot distinguish between the two defects
Omphalocele	41	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Congential hip dislocation	42	33	1	5	1	0	0	40	
Diaphragmatic hernia	43	9	2	2	0	0	0	13	
Trisomy 13 (Patau syndrome) - **Total**	44	7	0	1	0	0	0	8	
Trisomy 13 - Livebirths	44	7	0	1	0	0	0	8	
Trisomy 13 - Stillbirths	44	0	0	0	0	0	0	0	
Trisomy 13 - Terminations	44	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Trisomy 21 (Down syndrome) **Total**	45	57	4	13	14	1	0	89	
Trisomy 21 - Livebirths	45	57	4	13	14	1	0	89	
Trisomy 21 - Stillbirths	45	0	0	0	0	0	0	0	
Trisomy 21 - Terminations	45	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Trisomy 18 (Edwards syndrome) **Total**	46	11	0	1	1	0	0	13	
Trisomy 18 - Livebirths	46	3	0	1	1	0	0	5	
Trisomy 18 - Stillbirths	46	8	0	0	0	0	0	8	
Trisomy 18 - Terminations	46	N/A	N/A	N/A	N/A	N/A	N/A	N/A	
Fetus or newborn affected by maternal alcohol use	47	4	1	1	0	1	0	7	
Amniotic bands	48	N/A	N/A	N/A	N/A	N/A	N/A	N/A	No Code

Table 1a: Total Live Births by Race for 2004, 2005, 2006, 2007, 2008

Year	Denominator Data	Code	Non-Hispanic White	Non-Hispanic Black or African-American	Hispanic	Non-Hispanic Asian or Pacific Islander	Non-Hispanic American Indian or Alaska Native	Other/ Unknown	TOTAL	Comments
2004	Total Live Births	98	50,921	6,387	5,775	2,389	993	19	66,484	
2005	Total Live Births	98	50,689	6,592	6,122	2,553	990	24	66,970	
2006	Total Live Births	98	50,850	6,864	6,719	2,653	1,083	22	68,191	
2007	Total Live Births	98	50,891	7,084	6,780	2,829	1,107	28	68,719	
2008	Total Live Births	98	50,294	7,137	6,922	2,922	1,090	52	68,417	
2004-2008	Total Live Births	98	253,645	34,064	32,318	13,346	5,263	145	338,781	

Table 1b: Total Male Live Births by Race for 2004, 2005, 2006, 2007, 2008

Year	Denominator Data	Code	Non-Hispanic White	Non-Hispanic Black or African-American	Hispanic	Non-Hispanic Asian or Pacific Islander	Non-Hispanic American Indian or Alaska Native	Other/ Unknown	TOTAL	Comments
2004	Total Male Live Births	101	26,121	3,238	2,991	1,237	501	11	34,099	
2005	Total Male Live Births	101	26,007	3,316	3,119	1,344	503	13	34,302	
2006	Total Male Live Births	101	26,180	3,450	3,445	1,315	550	13	34,953	
2007	Total Male Live Births	101	26,106	3,598	3,464	1,420	569	15	35,172	
2008	Total Male Live Births	101	25,718	3,616	3,567	1,492	536	30	34,959	
2004-2008	Total Male Live Births	101	130,132	17,218	16,586	6,808	2,659	82	173,485	

Table 2: Trisomy Data by Age for 2004, 2005, 2006, 2007 and 2008

Year	Trisomy	Defect Code	Less than 35 years old	35 years old or greater	Unknown	Total*
2004-2008	Trisomy 13	44	19	8	0	27
2004-2008	Down syndrome	45	225	214	0	439
2004-2008	Trisomy 18	46	25	15	0	40
2004	Trisomy 13	44	3	0	0	3
2004	Down syndrome	45	36	48	0	84
2004	Trisomy 18	46	5	2	0	7
2005	Trisomy 13	44	2	3	0	5
2005	Down syndrome	45	34	39	0	73
2005	Trisomy 18	46	5	2	0	7
2006	Trisomy 13	44	6	0	0	6
2006	Down syndrome	45	48	38	0	86
2006	Trisomy 18	46	7	5	0	12
2007	Trisomy 13	44	5	0	0	5
2007	Down syndrome	45	62	45	0	107
2007	Trisomy 18	46	4	5	0	9
2008	Trisomy 13	44	3	5	0	8
2008	Down syndrome	45	45	44	0	89
2008	Trisomy 18	46	4	1	0	5

*Total should add up across rows. The total live birth defect should also match the total live births from the defect table.

Table 2a: Total Live Births by Age for 2004, 2005, 2006, 2007 and 2008

Year	Trisomy	Defect Code	Less than 35 years old	35 years old or greater	Unknown	Total*
2004	Total Live Births	98	57,419	9,064	1	66,484
2005	Total Live Births	98	57,930	9,037	3	66,970
2006	Total Live Births	98	59,001	9,180	10	68,191
2007	Total Live Births	98	59,751	8,965	3	68,719
2008	Total Live Births	98	59,732	8,664	21	68,417
2004-2008	Total Live Births	98	293,833	44,910	38	338,781

*Total should add up across rows. The total live birth defect should also match the total live births from the defect table.

Data comments:

Please include all general comments, including any major methodological changes, any year your registry was not collecting data, coding system used (ICD-9 or CDC/BPA), inclusion of stillbirths/terminations, probable/possible diagnoses, etc.

As in the past, Wisconsin used its linked birth-hospital discharge records. Live births that were not linked to a newborn discharge record are not included. Since the discharge records are only available from Wisconsin hospitals, only Wisconsin resident births occurring in Wisconsin hospitals are included.

The extracts used for previous years' reports were re-created from scratch, resulting in minor changes in the numbers of case found and changes in the total births included for 2002 and 2003. This re-extracting standardized the procedure across all years, eliminating minor differences that crept in with a new extract being defined for each new year.

The discharge records include a primary diagnosis and up to eight other diagnoses; all were scanned for the conditions. The diagnoses are ICD-9 coded.

Patent ductus arteriosus: the 2001-05 report erroneously had 0 cases for 2005 because the birthweight was not used. This has been corrected for the 2002-06 report.

Questions? richard.miller@wisconsin.gov

Attachment 3

Wisconsin Department of Health Services – Wisconsin WIC Program

Identification and Intervention for Infants and Children with Special Health Care Needs