Janet T. Mills
Governor

Jeanne M. Lambrew, Ph.D.
Commissioner

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January 10, 2020

Senator Geoffrey M. Gratwick, Chair
Representative Patricia Hymanson, Chair
Joint Standing Committee on Health and Human Services
100 State House Station
Augusta, Maine 04333-0100

Dear Senator Gratwick, Representative Hymanson and Members of the Joint Standing Committee on Health and Human Services:

Enclosed please find the 2019 Annual Report to the Legislature for the Maine CDC Birth Defects Program submitted by the Department of Health and Human Services. This report is required under Title 22 of the M.R.S.A., Chapter 1687. The report discusses the Birth Defects Program's activities and accomplishments in 2019 as well as planned activities for 2020.

Thank you for the opportunity to provide the Joint Committee on Health and Human Services with a report on the activities and accomplishments of the Maine CDC Birth Defects Program.

Sincerely,

Jeanne M. Lambrew

Jeanne M. Lambrew, Ph.D.
Commissioner

JML/klv

Enclosure

2019 Annual Report

Maine CDC Birth Defects Program

January 1, 2019 – December 31, 2019

Submitted to Joint Standing Committee on Health and Human Services

Acknowledgements

We would like to thank all Children with Special Health Needs staff, USM Epidemiologist and Vital Records for birth and death files, linkages and support for reporting. We thank all of Maine's reporting facilities for their time and efforts to provide the case reports that are essential to the success of this registry. We thank the members of the Maine CDC Birth Defect Advisory Committee for the partnership, advice and direction guiding and sustaining the program.

Contents

EXECUTIVE SUMMARY

December 2019

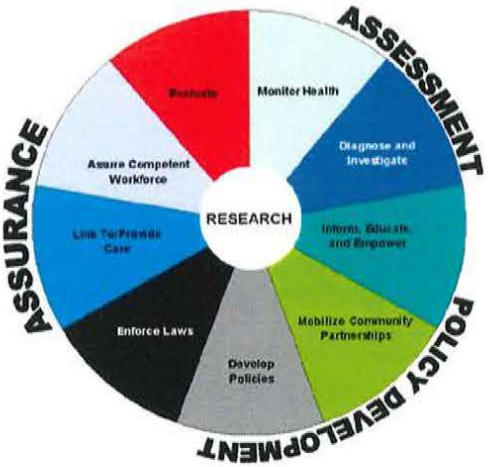
Background

In May 1999 the Department of Health and Human Services (DHHS) was authorized to collect information on birth defects in Maine by statute (Title 22: Health and Welfare: Subtitle: Facilities for Children and Adults; Chapter 1687; Birth Defects Program; §8941-§13375). The Maine CDC Birth Defects Program was established within the DHHS, Maine Center for Disease Control and Prevention (Maine CDC).

Purpose

The Maine CDC Birth Defects Program (BDP) focuses on the three public health core functions of assessment, assurance, and policy development in conjunction with the requirements set out in statute:

Provide an up-to-date birth defects registry that facilitates the identification of risk factors, assures epidemiology, protects confidentiality, determines reportable birth defects through an advisory committee, provides for primary prevention to decrease occurrence, maintains components to educate populations about birth defects and systems, and refers those with birth defects to early intervention and other support services.



Activities

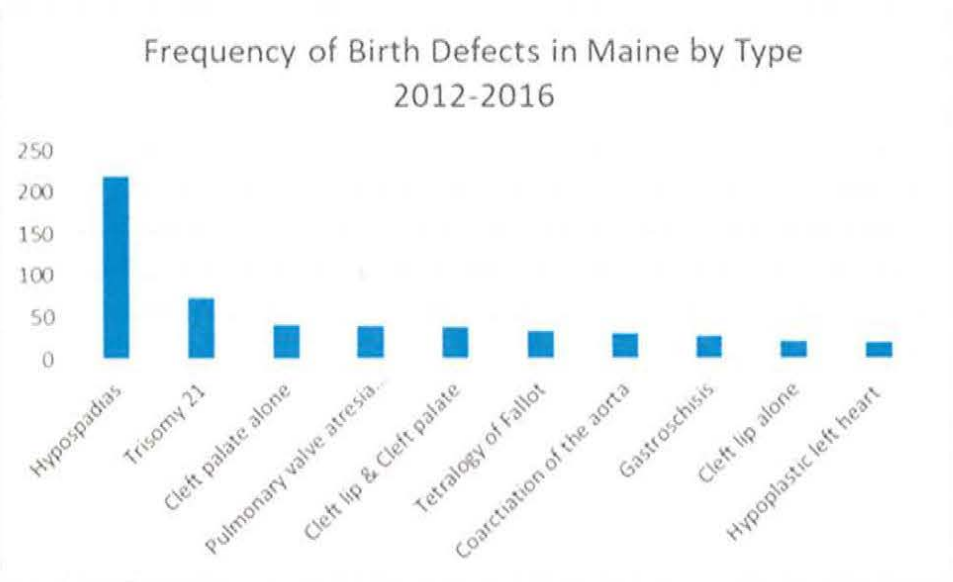
This 2019 Annual Report summarizes the current activities of the Maine CDC BDP, including ongoing and upcoming activities for calendar year 2020. In addition, selected birth defects counts and birth prevalence for the years 2012 through 2016 are provided. In 2019, the Maine CDC BDP:

- Completed and submitted the Annual Report of selected birth defects to the U.S. Centers for Disease Control and Prevention, National Birth Defect Prevention Network.
- Continued to make referrals for babies with a confirmed birth defect to the Maine Department of Education/Child Development Services (CDS) – Individuals with Disabilities Education Act (IDEA) Part C Agency.
- Met regularly with the Maine CDC Environmental Public Health Tracking Unit to discuss updates to the Environmental Tracking Portal related to birth defects.
- Met with the two abstractors who work with the Maine CDC BDP to develop skills.
- Provided educational materials about the prevention of birth defects to parents, health providers, and other interested parties.

- Convened the Maine CDC Birth Defects Advisory Committee to discuss relevant birth defect program issues and activities.
- Participated in the annual National Birth Defects Prevention Network Meeting, in March 2019
- Updated the Down Syndrome website, http://www.maine.gov/dhhs/mecdc/population-health/mch/cshn/birth-defects/families.html
- Continued to work with the Maine birthing hospitals to support them in sending critical congenital heart defects data electronically. Northern Light Eastern Maine Medical Center, MaineGeneral Medical Center and Central Maine Medical Center have developed a template and have been successful in submitting data electronically.
- Met with Cleft Lip and Palate Clinic Coordinators monthly to stay current with referrals and information.

Data

Hospitals report on 45 birth defects. Current birth defects counts and prevalence rates are for 2012 through 2016 due to a lag time for data integrity. The most frequently occurring birth defects in Maine are depicted in the chart below. The five most frequently occurring birth defects are Hypospadias, Trisomy 21, Cleft Palate (alone), Pulmonary Valve Atresia, and Cleft Lip and Palate (combined).



Future Direction

- Update Birth Defects Program Manual to reflect current scope of responsibilities.
- Expand, enhance, and strengthen the Advisory Committee.
- Increase collaboration with hospitals and community to expand reach of the Birth Defects Program.
- Continue to develop the Maine Newborn Screening Portal to ensure timely and accurate data are available.

For more information on the Maine CDC Birth Defects Program:
Contact Anna Cyr, Maternal and Child Health Coordinator, anna.cyr@maine.gov or 207-287-8424
http://www.maine.gov/dhhs/mecdc/population-health/mch/cshn/birth-defects/index.html

Maine Birth Defects Program Full Report

Background

A birth defect is defined as an abnormal condition that occurs before or at the time of birth. Birth defects include a wide range of abnormalities with varying levels of impact. Some birth defects are serious and can result in death, while others are less severe and can be treated with appropriate medical services. Birth defects may be caused by genetic factors, environmental, drug or medication exposures, while others remain unexplained. Birth defects can cause both mental and physical disabilities that affect children and their families for life. [1]

Birth defects affect about one in every 33 babies born in the United States each year. They are the leading cause of infant deaths, accounting for one in five infant deaths. Babies born with birth defects have a greater chance of illness and long-term disability than babies born without birth defects.[2] In order to prevent birth defects, it is essential to know what types of birth defects are occurring. A population-based birth defects surveillance program that uses multiple sources of data allows a surveillance program to accurately quantify morbidity and mortality, detect temporal trends, and assess the financial burden on families and State programs that birth defects may cause.[3] Many children who survive have a lifetime of major expenses from essential services such as specialty medical care, special education, rehabilitation and developmental services.

The Maine CDC BDP is committed to fulfilling its mission that all infants with birth defects are identified early and referred to an established network of services in order to achieve optimal health and develop to their fullest potential. The Maine CDC BDP is a comprehensive surveillance program that benefits the residents of Maine through the early identification of infants who have birth defects. Early identification ensures timely and appropriate access to systems of care that are family-centered, culturally competent, and community-based. It is the intention of the Maine CDC BDP to participate fully in epidemiological investigations as a means of informing public policy, to develop prevention strategies in order to reduce birth defects and to assess for timely referrals and follow-up care to reduce mortality and morbidity among children identified with birth defects.

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[1] Trust for America's Health "Birth defects and Developmental Disabilities: A Major Public Health Challenge"
[2] https://www.cdc.gov/ncbddd/birthdefects/index.html
[3] National Birth Defects Prevention Network http://www.nbdpn.org/

Legislation and Rules

Legislation supporting the Maine CDC BDP has and continues to define the purpose of the program. The statutes defining these roles and responsibilities are listed below.

May 1999 - Public Law (P.L.) 1322, 22 M.R.S.A. c. 1687, established the Maine CDC BDP within the Maine DHHS. Program rules were formally adopted April 2003 outlining reporting responsibilities and access to medical records. Mandated reporting began May 2003.

May 2008 – Rules were updated to include three additional reportable birth defects.

April 2011 – Rules were amended to include the 45 birth defects recommended by the U. S. CDC and the National Birth Defects Prevention Network. Referral to the Part C Agency, Child Developmental Services (CDS) was also included.

December 2017 – Rules amended to include additional birth defects recommended by the U.S. CDC and the National Birth Defects Prevention Network.

Stakeholders

Organizations that have a strong association with the Maine CDC BDP:

Consumers ○ Parents and families	**Early Intervention Agencies** ○ Department of Education – Child Development Services
External groups involved with screening, follow-up, and diagnosis ○ Hospitals and their staff ○ Nurses ○ Primary care providers ○ Specialist physicians ○ Genetic counselors	**Other DHHS Programs** ○ Maine CDC Newborn Hearing Screening Program ○ Maine CDC Newborn Bloodspot Screening Program ○ Maine CDC Environmental Public Health Tracking ○ Maine CDC Data, Research and Vital Statistics ○ Office of MaineCare Services ○ Pregnancy Risk Assessment Monitoring System
The March of Dimes and the National Birth Defects Prevention Network are key national-level partners.	

Maine CDC Birth Defects Advisory Committee

The Advisory Committee meets at least annually and more frequently, if needed. The Committee consists of Maine CDC Children with Special Health Needs staff, health professionals, and representation from other state, community and private sector agencies. The group provides consultation to the Maine CDC BDP on development, implementation and evaluation of program policies, procedures and activities.

Summary of Activities

The Maine CDC Birth Defects Committee met once this past year. Items discussed included:

- Review of options to share existing data with interested parties

- Methods to reach out to families and other interested parties to spread the word about birth defects prevention
- Updates to the implementation of Critical Congenital Heart Defects (CCHD) screening and follow up within New England and Maine
- Possible National Birth Defects Prevention Network study related to folic acid and spina bifida
- Expanding the membership of the Committee
- Reviewing and updating the birth defects program procedures as they relate to the updated rules and other changes
- Inviting specialists to speak to increase knowledge of reportable birth defects

Maine CDC Birth Defects Program Summary

Program Description

The Maine CDC BDP began developing a birth defects surveillance system in 1999 with funding from the U.S. Centers for Disease Control and Prevention (CDC). The Maine CDC BDP was established within the Maine CDC to identify newborns with birth defects, ensure they receive appropriate specialty services, and monitor birth defect trends.

As a surveillance unit, the Maine CDC BDP began passive case ascertainment with confirmation of cases by active case ascertainment on May 1, 2003. Passive case ascertainment with active case ascertainment is an approach whereby the surveillance program receives case reports of birth defects from a variety of data sources and then follows up with a review of the case. As required by statute, those entities licensed under Title 22: Hospitals and Title 32: Licensed Professionals are required to provide or make available health records and information relating to the occurrence of birth defects. Passive data sources include hospital case reports, birth and death certificates, and medical discharge records using diagnostic codes. Once a case is identified as a possible reportable birth defect, the case is assigned to an abstractor. The abstractor requests records and reviews them to confirm the presence of a birth defect.

The Maine CDC BDP is aligned with the most current listing of reportable birth defects to reflect the birth defects surveillance guidelines developed by the CDC National Birth Defects Prevention Network. The current listing of reportable birth defects may be found in Appendix A.

The Maine CDC BDP currently receives medical discharge data electronically from all birthing hospitals. Maine CDC BDP sends all hospitals a monthly electronic reminder to submit data.

For a case to be considered by the Maine CDC BDP, it must meet one or more of the following criteria:

- Infant was live born, stillborn, or prenatally diagnosed, with a gestational age of greater than 20 weeks
- Fetuses less than 20 weeks gestation, but with a prenatal diagnosis
- Birth occurred in Maine and the mother was a Maine resident
- Diagnosis was made before the infant reached 1 year of age

- Birth defect is included in the Maine CDC BDP list of reportable birth defects

Potential cases are identified through weekly downloads of both the electronic birth and infant death certificates and medical records discharge data. Once a potential case is identified, abstraction is performed using a comprehensive electronic abstraction method. Information collected includes the nature and details of the birth defect, demographics, mother's health history, prenatal information, cytogenic and laboratory data, family history, and, when available, father's history, and mother's exposure to illegal drugs, medications, smoking, or alcohol.

The data collected by the abstractors is reviewed and entered in the birth defects surveillance and tracking system. The system houses data obtained from hospitals, health care providers, and others mandated to report birth defects.

Currently, the Maine CDC BDP reports on and gathers information on 45 birth defects (see Appendix A for a list of reportable birth defects). These cases are confirmed usually within the first three months after birth. However, this timeframe can be longer depending on when the birth defect was reported and the ability of the abstractors to gather the necessary information from the birth hospital. There is also a lag time in verifying a birth defect because, by law, a birth defect can be diagnosed and reported within the first year of life.

Personnel and Funding Sources

The Maine CDC BDP consists of 1 FTE coordinator and .12 FTE Epidemiologist. The Maine CDC BDP currently contracts with partners to provide data registry abstraction services and to facilitate the Cleft Lip and Palate clinical services.

The Maine CDC BDP and contracted services are funded by state and federal funds allocated to promoting and improving the health and well-being of the Maine's mothers, children, including children with special needs, and their families.

Goals, Activities, and Achievements

The Maine CDC BDP gathers data about infants born each year with certain birth defects diagnosed within the first year of life. The statute requires that the Maine CDC BDP:

- Collect, analyze, and distribute information to identify the birth defects with regards to the following: causes, risk factors, and strategies for prevention and the provision of services
- Establish a system for data collection that identifies prevalence and incidence rates by region and population group and identifies the morbidity and mortality rates resulting from birth defects
- Conduct investigations to determine the nature and extent of the disease or known or suspected causes of birth defects
- Examples of Maine CDC BDP activity:
    - Collection and abstraction of data on 45 birth defects. The Maine CDC BDP submits data annually to the National Birth Defects Prevention Network and U.S. CDC.

- Collaboration with the Maine CDC Environmental Public Health Tracking Unit to show 12 of the 45 birth defects on the Environmental Health Tracking Portal.
- The baby identified with a confirmed birth defect is referred to the Department of Education Part C Agency (CDS) for follow-up for early intervention services.

Cleft Lip and Palate

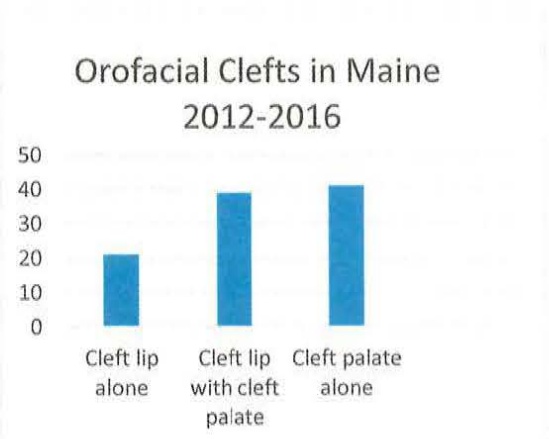
The Maine CDC BDP currently supports and collaborates with Cleft Lip and Palate clinics at Maine Medical Center and Northern Light Eastern Maine Medical Center. All families with a prenatal or postnatal diagnosis are offered a visit from a Public Health Nurse who provides support, answers questions, and connects families with the Cleft Lip and Palate clinics. Families may attend clinic until the child turns 22 years of age regardless of income. Families attending clinics have access to multidisciplinary teams including a geneticist, genetic counselor, plastic surgeon, oral surgeon, prosthodontist, orthodontist, pediatric dentist, otolaryngologist (ears, nose, and throat) nurse practitioner, speech pathologist, social worker, and clinic coordinator. This team of specialists works collaboratively with families to develop the best treatment plan for each child's condition.

Children with cleft lip and palate can find comprehensive care at Maine's Cleft Lip and Palate Clinic locations. This year, each site began working toward becoming an American Cleft Palate-Craniofacial Association approved team. Clinic sites also provide a full range of education and consultation services upon request in addition to monthly clinical services. Additionally, clinical sites are working to provide family and community educational opportunities on an annual basis. In 2019, more than 100 families received services at 19 clinical sessions.

LEFT LIP AND CLEFT PALATE ARE BIRTH DEFECTS THAT OCCUR WHEN A BABY'S LIP OR MOUTH DO NOT FORM PROPERLY DURING PREGNANCY. TOGETHER, THESE BIRTH DEFECTS COMMONLY ARE CALLED "OROFACIAL CLEFTS".

Baby with cleft lip

Baby with cleft palate



Maine CDC Birth Defects Tracking System

Tracking System

Maine CDC BDP began collaborating with Nebulogic in 2019 to develop and implement a new comprehensive surveillance and tracking system. The Maine Newborn Screening Portal (MNSP) links birth defect data with multiple data sources that include birth and death certificates, hospital discharge data, and metabolic and newborn hearing screening data. MNSP maintains confidentiality of all records by assigning permission to access the system on an individual basis. By linking information from these existing data sources, the Maine CDC BDP can provide valuable public health data to state and national policy makers.

Statistical Reports

The Maine CDC BDP submits data annually for a specific span of years to the U.S. CDC, National Birth Defects Prevention Network. The most recent data submitted to the U.S. CDC was 2012-2016, which was available for publication in November 2019. The 24-month lag time in U.S. CDC data is based on the definition of a birth defect. A birth defect meets criteria and is included in the Maine CDC BDP count if the birth defect is identified within the first year of life. This means that the Maine CDC BDP may still be gathering data as late as December of the year after the birth of the baby. Consequently, time is needed to abstract the data necessary to confirm the birth defect.

Appendices

Appendix A

Reportable Birth Defects Included in Case Definition for 2019

Birth Defect	ICD-10-CM Codes
Central Nervous System	
Anencephalus	Q00.0-Q00.1
Spina Bifida without anencephalus	Q05.0-Q05.9 Q07.01, Q07.03 w/o Q00.0-Q00.1
Hydrocephalus without Spina Bifida	Q03-Q03.9
Encephalocele	Q01-Q01.9
Microcephalus	Q02
Holoprosencephaly	Q04.2
Eye	
Anophthalmia/microphthalmia	Q11.0-Q11.2
Congenital cataract	Q12.0
Aniridia	Q13.1
Ear	
Anotia/microtia	Q16.0, Q17.2
Cardiovascular	
Common truncus (truncus arteriosus or TA)	Q20.0
Double outlet right ventricle (DORV)	Q20.1
Interrupted aortic arch (IAA)	Q25.2, Q25.4
Transposition of great arteries	Q20-Q20.9
Tetralogy of Fallot	Q21.3
Ventricular septal defect	Q21.0
Atrial septal defect	Q21.1
Atrioventricular septal defect (Endocardial cushion defect)	Q21.2
Pulmonary valve atresia and stenosis	Q22.0, 22.1
Tricuspid valve atresia and stenosis	Q22.4
Ebstein's anomaly	Q22.5
Aortic valve stenosis	Q23.0
Hypoplastic left heart syndrome	Q23.4
Patent ductus arteriosus	Q25.0
Coarctation of aorta	Q25.1
Total anomalous pulmonary venous connection (TAPVC)	Q26.2
Single Ventricle	Q20.4
Orofacial	
Cleft palate without cleft lip	Q35.1 - Q35.9
Cleft lip with and without cleft palate	Q36.0 - 36.9, Q37.0 - Q37.9
Choanal atresia	Q30.0
Gastrointestinal	
Esophageal atresia/tracheoesophageal fistula	Q39.0 - 39.4
Rectal and large intestinal atresia/stenosis	Q42.0 - Q42.9
Pyloric stenosis	Q40.0
Hirshsprung's disease (congenital megacolon)	Q43.1
Biliary atresia	Q44.2 – Q44.3

Small intestinal atresia/stenosis	Q41.0 – Q41.9
Genitourinary	
Renal agenesis/hypoplasia	Q60 – Q60.6
Bladder exstrophy	Q64.10 – Q64.19
Obstructive genitourinary defect	Q62 – 62.39, Q64.2
Hypospadias and Epispadias	Q51.0 - Q54.9 (excluding Q54.4)
Cloacal exstrophy	Q64.12
Congenital Posterior Urethral Valves	Q64.2
Musculoskeletal	
Reduction deformity, upper limbs	Q71.0-Q71.9, 73.0 – Q73.8
Reduction deformity, lower limbs	Q72.0- Q72.9
Gastroschisis	Q79.3
Omphalocele	Q79.2
Congenital hip dislocation	Q65 – Q65.5
Diaphragmatic hernia	Q79.0, Q79.1
Clubfoot	Q66.0, Q66.89
Craniosynostosis	Q75.0
Chromosomal	
Trisomy 13	Q91.4 – Q91.7
Down Syndrome (Trisomy 21)	Q90.0 – Q90.9
Trisomy 18	Q91.0 – Q91.3
Deletion 22q11	Q93.81
Turner syndrome	Q96.0 – Q96.9
Other	
Fetal alcohol syndrome	Q86.0
Amniotic bands	No code

Appendix B

Birth Defects Counts and Prevalence Rates (2012-2016), Maine				
Condition	**Summary**	**Five Year Count**	**Prevalence per 10,000 Live Births And 95% Confidence Interval**	**Data Period**
Anencephalus	One in 4,542 live births	14	2.2 (1.2-3.7)	2012-2016
Anotia/microtia	One in 4,891 live births	13	2.0 (1.1-3.5)	2012-2016
Cleft lip alone	One in 3,028 live births	21	3.3 (2.0-5.0)	2012-2016
Cleft lip with cleft palate	One in 1,630 live births	39	6.1 (4.4-8.4)	2012-2016
Cleft palate alone	One in 1,551 live births	41	6.4 (4.6-8.7)	2012-2016
Coarctation of the aorta	One in 2,119 live births	30	4.7 (3.2-6.7)	2012-2016
Common truncus (truncus arteriosus)	---	0	---	2012-2016
Encephalocele	One in 7,948 live births	8	1.3 (0.5-2.5)	2012-2016
Gastroschisis	One in 2,355 live births	27	4.2 (2.8-6.2)	2012-2016
Hypoplastic left heart syndrome	One in 3,179 live births	20	3.1 (1.9-4.9)	2012-2016
Hypospadias*	One in 150 live births	219	66.8 (58.3-76.3)	2012-2016
Limb deficiencies (reduction defects)	One in 3,347 live births	19	3.0 (1.8-4.7)	2012-2016
Omphalocele	One in 7,948 live births	8	1.3 (0.5-2.5)	2012-2016
Pulmonary valve atresia	One in 7,065 live births	9	1.4 (0.6-2.7)	2012-2016
Pulmonary valve atresia and stenosis	One in 1,590 live births	40	6.3 (4.5-8.6)	2012-2016
Spina bifida without anencephalus	One in 3,974 live births	16	2.5 (1.4-4.1)	2012-2016
Tetralogy of Fallot	One in 1,870 live births	34	5.3 (3.7-7.5)	2012-2016
Transposition of the great arteries (TGA)	One in 3,532 live births	18	2.8 (1.7-4.5)	2012-2016
Tricuspid valve atresia and stenosis	One in 12,717 live births	3	0.5 (0.1-1.4)	2012-2016
Trisomy 21 (Down syndrome)	One in 871 live births	73	11.5 (9.0-14.4)	2012-2016
Total Live Births 2012-2016		*63,584*		
Total Male Live Births 2012-2016		*32,768*		
Notes				

Count and rates are based on five years of available data for each condition during the reporting period 2012-2016.

*Hypospadias: prevalence per 10,000 male live births; total male live births are provided for Hypospadias rates.

Data Sources:
Birth Defects: Maine Birth Defects Registry, extract May 2019.
Births: United States Department of Health and Human Services (US DHHS), Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS), Division of Vital Statistics, Natality public-use data 2007-2016, CDC WONDER Online Database, May 2019. Accessed at **http://wonder.cdc.gov/natality-current.html.** Due to birth datafile limitations, total births include babies born to Maine residents in and out of state.

General comments: Case-finding is limited to babies born in Maine to Maine residents and to birth defects identified in the first year of life and fetal deaths. A baby can be born with multiple conditions, adding up the number of defects will not yield the number of babies born with defects. In addition, this list represents only a portion of reportable birth defects collected and tracked in Maine.
National birth defects data can be found at the following link: http://www.nbdpn.org/annual_reports.php

Birth Defects Counts and Prevalence Rates (2013-2016), Maine

Conditions for which Maine Birth Defects Registry began surveillance in 2013

Condition	Summary	Four Year Count	Prevalence per 10,000 Live Births And 95% Confidence Interval	Data Period
Anophthalmia/microphthalmia	One in 25,393 live births	2	0.4 (0.0-1.4)	2013-2016
Aortic valve stenosis	One in 12,697 live births	4	0.8 (0.2-2.0)	2013-2016
Atrial septal defect	One in 353 live births	144	28.4 (23.9-33.4)	2013-2016
Atrioventricular septal defect (Endocardial cushion defect)	One in 3,174 live births	16	3.2 (1.8-5.1)	2013-2016
Biliary atresia	---	0	---	2013-2016
Bladder exstrophy	One in 25,393 live births	2	0.4 (0.0-1.4)	2013-2016
Congenital cataract	One in 16,929 live births	3	0.6 (0.1-1.7)	2013-2016
Diaphragmatic hernia	One in 19,041 live births	2	0.4 (0.0-1.4)	2013-2016
Ebstein anomaly	One in 50,786 live births	1	0.2 (0.0-1.1)	2013-2016
Esophageal atresia/tracheoesophageal fistula	One in 3,628 live births	14	2.8 (1.5-4.6)	2013-2016
Rectal and large intestinal atresia/stenosis	One in 2,031 live births	25	4.9 (3.2-7.3)	2013-2016
Renal agenesis/hypoplasia	One in 1,539 live births	33	6.5 (4.5-9.1)	2013-2016
Trisomy 13	One in 25,393 live births	2	0.4 (0.0-1.4)	2013-2016
Trisomy 18	One in 7,255 live births	7	1.4 (0.6-2.8)	2013-2016
Ventricular septal defect	One in 493 live births	103	20.3 (16.6-24.6)	2013-2016

Total Live Births 2013-2016	*50,786*

Notes

Surveillance for this list of conditions began in 2013. *Count and rates are based on* ***three*** *years of available data for each condition during the reporting period 2013-2016.*

Total live births and total male live births include babies born to Maine residents in and out of state.

Data Sources:

Birth Defects: Maine Birth Defects Registry, extract May 2019.

Births: United States Department of Health and Human Services (US DHHS), Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS), Division of Vital Statistics, Natality public-use data 2007-2016, CDC WONDER Online Database, May 2019. Accessed at **http://wonder.cdc.gov/natality-current.html.** Due to birth datafile limitations, total births include babies born to Maine residents in and out of state.

General comments: Case-finding is limited to babies born in Maine to Maine residents and to birth defects identified in the first year of life and fetal deaths.. A baby can be born with multiple conditions, adding up the number of defects will not yield the number of babies born with defects. In addition, this list represents only a portion of reportable birth defects collected and tracked in Maine. National birth defects data can be found at the following link: http://www.nbdpn.org/annual_reports.php

The Department of Health and Human Services (DHHS) does not discriminate on the basis of disability, race, color, creed, gender, sexual orientation, age, or national origin, in admission to, access to, or operations of its programs, services, or activities, or its hiring or employment practices. This notice is provided as required by Title II of the Americans with Disabilities Act of 1990 and in accordance with the Civil Rights Act of 1964 as amended, Section 504 of the Rehabilitation Act of 1973, as amended, the Age Discrimination Act of 1975, Title IX of the Education Amendments of 1972 and the Maine Human Rights Act and Executive Order Regarding State of Maine Contracts for Services. Questions, concerns, complaints or requests for additional information regarding the ADA may be forwarded to DHHS' ADA Compliance/EEO Coordinators, 11 State House Station – 221 State Street, Augusta, Maine 04333, 207-287-4289 (V), 207-287-3488 (V), TTY users call Maine relay 711. Individuals who need auxiliary aids for effective communication in program and services of DHHS are invited to make their needs and preferences known to the ADA Compliance/EEO Coordinators. This notice is available in alternate formats, upon request.