Maine

Maine CDC Birth Defects Program (MBDP)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services, Education
Partner: Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs, March of Dimes, Maine Tracking Network
Program status: Currently collecting data
Start year: 1999
Earliest year of available data: 2003
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 12,000
Statewide: Yes
Current legislation or rule: 22 MRSA c. 1687
Legislation year enacted: 1999

Case Definition

Outcomes covered: Selected major birth defects: NTD, clefts, gastroschisis, omphalocele, trisomy 21, reduction deformities of upper and lower limb, hypospadias and major heart defects
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (Less than 20 weeks gestation, 20 weeks gestation and greater, Prenatally diagnosed at any gestation), Elective terminations (Prenatally diagnosed at any gestation)
Age: Through age 1
Residence: All in-state births to Maine residents

Surveillance Methods

Case ascertainment: Passive case ascertainment with active case confirmation
Vital records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program
Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetic facilities, Maternal serum screening facilities
Other sources: Midwifery Facilities, Physician reports, Children with Special Health Needs

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with an ICD-9-CM code 740-759/ICD-10-CM code Q00-Q99, Any birth certificate with a birth defect box checked, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), All stillborn infants, All infants in NICU or special care nursery, All prenatally diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Cardiovascular condition, Any infant with a codable defect
Coding: ICD-9-CM/ICD-10-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history

Data Collection Methods and Storage

Data collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Electronic scanning of printed records
Database collection and storage: Oracle, Microsoft SQL Server

Data Analysis

Data analysis software: SAS
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Timeliness
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration

System links: Link to other Maine state registries/databases, Link case finding data to final birth file
System integration: Newborn Hearing/ Newborn Bloodspot Screening Programs

Funding

Funding source: 100% MCH funds

Other

Web site:
http://www.maine.gov/dhhs/mecdc/population-health/mch/cshn/birth-defects/index.html

Contacts

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DATA TABLES

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Birth Defects Counts and Prevalence 2014 - 2017 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total***	**Notes**
Anencephalus	11	0	0	0	1	12	1
	2.5	***0.0***	***0.0***	***0.0***	***18.3***	***2.5***	
Anophthalmia/microphthalmia	3	0	0	0	0	3	
	0.7	***0.0***	***0.0***	***0.0***	***0.0***	***0.6***	
Anotia/microtia	9	0	0	0	0	9	
	2.0	***0.0***	***0.0***	***0.0***	***0.0***	***1.8***	
Aortic valve stenosis	5	1	0	0	0	6	
	1.1	***5.3***	***0.0***	***0.0***	***0.0***	***1.2***	
Atrial septal defect	104	8	3	0	1	120	
	23.4	***42.5***	***34.6***	***0.0***	***18.3***	***24.6***	
Atrioventricular septal defect (Endocardial cushion defect)	13	1	0	0	1	17	
	2.9	***5.3***	***0.0***	***0.0***	***18.3***	***3.5***	
Biliary atresia	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Bladder exstrophy	2	0	0	0	0	2	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.4***	
Choanal atresia	4	0	0	0	0	4	
	0.9	***0.0***	***0.0***	***0.0***	***0.0***	***0.8***	
Cleft lip alone	17	0	0	0	0	18	
	3.8	***0.0***	***0.0***	***0.0***	***0.0***	***3.7***	
Cleft lip with cleft palate	29	0	1	0	1	31	
	6.5	***0.0***	***11.5***	***0.0***	***18.3***	***6.4***	
Cleft palate alone	28	1	2	0	0	31	
	6.3	***5.3***	***23.1***	***0.0***	***0.0***	***6.4***	
Cloacal exstrophy	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Coarctation of the aorta	22	1	0	0	0	23	
	4.9	***5.3***	***0.0***	***0.0***	***0.0***	***4.7***	
Common truncus (truncus arteriosus)	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Congenital cataract	3	1	0	0	0	4	
	0.7	***5.3***	***0.0***	***0.0***	***0.0***	***0.8***	
Diaphragmatic hernia	2	0	0	0	0	2	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.4***	
Ebstein anomaly	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Encephalocele	5	0	0	0	0	5	
	1.1	***0.0***	***0.0***	***0.0***	***0.0***	***1.0***	
Esophageal atresia/tracheoesophageal fistula	11	0	0	0	0	12	
	2.5	***0.0***	***0.0***	***0.0***	***0.0***	***2.5***	
Gastroschisis	13	1	1	0	2	18	
	2.9	***5.3***	***11.5***	***0.0***	***36.7***	***3.7***	
Hypoplastic left heart syndrome	8	0	0	0	0	8	
	1.8	***0.0***	***0.0***	***0.0***	***0.0***	***1.6***	
Hypospadias	141	4	2	0	1	154	2
	61.9	***43.0***	***43.6***	***0.0***	***34.8***	***61.6***	
Limb deficiencies (reduction defects)	10	0	0	0	0	11	
	2.2	***0.0***	***0.0***	***0.0***	***0.0***	***2.3***	
Omphalocele	7	0	0	0	0	7	
	1.6	***0.0***	***0.0***	***0.0***	***0.0***	***1.4***	
Pulmonary valve atresia and stenosis	20	2	0	0	0	23	
	4.5	***10.6***	***0.0***	***0.0***	***0.0***	***4.7***	
Pulmonary valve atresia	5	1	0	0	0	6	
	1.1	***5.3***	***0.0***	***0.0***	***0.0***	***1.2***	
Rectal and large intestinal atresia/stenosis	20	1	0	0	0	22	
	4.5	***5.3***	***0.0***	***0.0***	***0.0***	***4.5***	
Renal agenesis/hypoplasia	30	0	1	0	0	31	
	6.7	***0.0***	***11.5***	***0.0***	***0.0***	***6.4***	
Spina bifida without anencephalus	16	0	0	0	0	16	
	3.6	***0.0***	***0.0***	***0.0***	***0.0***	***3.3***	

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Birth Defects Counts and Prevalence 2014 - 2017 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total***	**Notes**
Tetralogy of Fallot	21	0	1	0	0	22	
	4.7	***0.0***	***11.5***	***0.0***	***0.0***	***4.5***	
Transposition of the great arteries (TGA)	11	1	1	0	0	13	
	2.5	***5.3***	***11.5***	***0.0***	***0.0***	***2.7***	
Tricuspid valve atresia and stenosis	2	1	0	0	0	3	
	0.4	***5.3***	***0.0***	***0.0***	***0.0***	***0.6***	
Tricuspid valve atresia	2	0	0	0	0	2	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.4***	
Trisomy 13	1	0	0	0	0	1	
	0.2	***0.0***	***0.0***	***0.0***	***0.0***	***0.2***	
Trisomy 18	8	0	0	0	0	8	
	1.8	***0.0***	***0.0***	***0.0***	***0.0***	***1.6***	
Trisomy 21 (Down syndrome)	50	4	1	0	2	62	
	11.2	***21.3***	***11.5***	***0.0***	***36.7***	***12.7***	
Ventricular septal defect	78	4	2	0	0	87	
	17.5	***21.3***	***23.1***	***0.0***	***0.0***	***17.8***	
Total live births	**44,486**	**1,881**	**866**	**836**	**545**	**48,796**	**3**
Male live births	**22,793**	**930**	**459**	**447**	**287**	**25,009**	

Maine

Birth Defects Counts and Prevalence 2014 - 2017 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	18	0	18	
	4.4	***0.0***	***3.7***	
Trisomy 13	0	1	1	
	0.0	***1.3***	***0.2***	
Trisomy 18	3	5	8	
	0.7	***6.7***	***1.6***	
Trisomy 21 (Down syndrome)	34	24	62	
	8.2	***32.0***	***12.7***	
Total live births	**41,296**	**7,496**	**48,796**	**3**

Notes

1. Data for this condition include probable cases.
2. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births.
3. Data for total live births include unknown gender.

General comments

*Data for totals include unknown and/or other.