

Virginia

Virginia Congenital Anomalies and Reporting Education System (VaCARES)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services

Partner: Local Health Departments, Hospitals

Program status: Currently collecting data

Start year: 1985

Earliest year of available data: 2004

Organizational location: Department of Health (Office of Family Health Services, Division of Child and Family Health)

Population covered annually: 94,650

Statewide: Yes

Current legislation or rule: Code of Virginia, § 32.1-69.1 <https://law.lis.virginia.gov/vacodefull/title32.1/chapter2/article8.1/>

Legislation year enacted: 1985

Case Definition

Outcomes covered: Major and non-major birth defects

Pregnancy outcome: Livebirths (All gestational ages and birth weights)

Age: Up to 2 years of age

Residence: Any diagnoses occurring in-state

Surveillance Methods

Case ascertainment: Passive case-finding without case confirmation

Vital records: Birth certificates

Other state based registries: Newborn hearing screening program, Newborn metabolic screening program

Delivery hospitals: Discharge summaries

Pediatric & tertiary care hospitals: Discharge summaries

Other specialty facilities: Genetic counseling/clinic genetic facilities

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease)

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.), Infant complications, 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, Pregnancy/delivery complications, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.)

Database collection and storage: Web-based reporting system is linked to electronic birth certificate and populates Oracle data tables

Data Analysis

Data analysis software: SAS

Data use and analysis: Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Epidemiological studies (using only program data), Needs assessment, Referral, Grant proposals, Education/public awareness

System Integration

System links: Link to other state registries/databases, Link case finding data to final birth file

System integration: VaCARES is part of the Virginia Vital Events Screening and Tracking System, which also houses electronic birth certificate reporting and the Virginia Early Hearing Detection and Intervention tracking systems.

Funding

Funding source: 100% MCH funds

Other

Web site: <https://www.vdh.virginia.gov/vacares/>

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DATA TABLES

Virginia
Birth Defects Counts and Prevalence 2014 - 2018 (Prevalence per 10,000 Live Births)

Defect	Maternal Race/Ethnicity					Total*	Notes
	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic		
Anencephalus	15 <i>0.5</i>	4 <i>0.4</i>	4 <i>0.6</i>	3 <i>0.9</i>	0 <i>0.0</i>	29 <i>0.6</i>	
Anophthalmia/microphthalmia	22 <i>0.8</i>	11 <i>1.0</i>	2 <i>0.3</i>	2 <i>0.6</i>	0 <i>0.0</i>	39 <i>0.8</i>	
Anotia/microtia	31 <i>1.1</i>	9 <i>0.8</i>	11 <i>1.7</i>	5 <i>1.5</i>	0 <i>0.0</i>	58 <i>1.2</i>	
Aortic valve stenosis	38 <i>1.4</i>	3 <i>0.3</i>	7 <i>1.1</i>	3 <i>0.9</i>	1 <i>11.4</i>	52 <i>1.0</i>	
Atrial septal defect	3,247 <i>116.1</i>	1,682 <i>157.6</i>	1,135 <i>171.9</i>	375 <i>115.5</i>	10 <i>114.2</i>	6,683 <i>132.6</i>	
Atrioventricular septal defect (Endocardial cushion defect)	105 <i>3.8</i>	43 <i>4.0</i>	39 <i>5.9</i>	6 <i>1.8</i>	0 <i>0.0</i>	203 <i>4.0</i>	
Biliary atresia	48 <i>1.7</i>	36 <i>3.4</i>	19 <i>2.9</i>	4 <i>1.2</i>	0 <i>0.0</i>	111 <i>2.2</i>	
Bladder exstrophy	3 <i>0.1</i>	0 <i>0.0</i>	1 <i>0.2</i>	0 <i>0.0</i>	0 <i>0.0</i>	5 <i>0.1</i>	
Choanal atresia	37 <i>1.3</i>	10 <i>0.9</i>	2 <i>0.3</i>	3 <i>0.9</i>	0 <i>0.0</i>	53 <i>1.1</i>	
Cleft lip alone	79 <i>2.8</i>	16 <i>1.5</i>	16 <i>2.4</i>	7 <i>2.2</i>	0 <i>0.0</i>	126 <i>2.5</i>	
Cleft lip with cleft palate	133 <i>4.8</i>	27 <i>2.5</i>	30 <i>4.5</i>	16 <i>4.9</i>	0 <i>0.0</i>	210 <i>4.2</i>	
Cleft palate alone	196 <i>7.0</i>	45 <i>4.2</i>	20 <i>3.0</i>	11 <i>3.4</i>	1 <i>11.4</i>	278 <i>5.5</i>	
Cloacal exstrophy	50 <i>1.8</i>	28 <i>2.6</i>	12 <i>1.8</i>	4 <i>1.2</i>	0 <i>0.0</i>	100 <i>2.0</i>	
Clubfoot	381 <i>13.6</i>	136 <i>12.7</i>	69 <i>10.5</i>	34 <i>10.5</i>	2 <i>22.8</i>	648 <i>12.9</i>	
Coarctation of the aorta	177 <i>6.3</i>	61 <i>5.7</i>	47 <i>7.1</i>	12 <i>3.7</i>	1 <i>11.4</i>	304 <i>6.0</i>	
Common truncus (truncus arteriosus)	17 <i>0.6</i>	4 <i>0.4</i>	2 <i>0.3</i>	1 <i>0.3</i>	0 <i>0.0</i>	25 <i>0.5</i>	
Congenital cataract	25 <i>0.9</i>	19 <i>1.8</i>	8 <i>1.2</i>	4 <i>1.2</i>	0 <i>0.0</i>	61 <i>1.2</i>	
Congenital posterior urethral valves	21 <i>1.5</i>	17 <i>3.1</i>	4 <i>1.2</i>	1 <i>0.6</i>	0 <i>0.0</i>	43 <i>1.7</i>	1
Craniosynostosis	156 <i>5.6</i>	30 <i>2.8</i>	22 <i>3.3</i>	6 <i>1.8</i>	0 <i>0.0</i>	217 <i>4.3</i>	
Deletion 22q11.2	7 <i>0.3</i>	4 <i>0.4</i>	4 <i>0.6</i>	1 <i>0.3</i>	0 <i>0.0</i>	16 <i>0.3</i>	
Diaphragmatic hernia	69 <i>2.5</i>	35 <i>3.3</i>	16 <i>2.4</i>	5 <i>1.5</i>	0 <i>0.0</i>	127 <i>2.5</i>	
Double outlet right ventricle	47 <i>1.7</i>	32 <i>3.0</i>	18 <i>2.7</i>	7 <i>2.2</i>	0 <i>0.0</i>	108 <i>2.1</i>	
Ebstein anomaly	19 <i>0.7</i>	8 <i>0.7</i>	5 <i>0.8</i>	3 <i>0.9</i>	0 <i>0.0</i>	35 <i>0.7</i>	
Encephalocele	13 <i>0.5</i>	3 <i>0.3</i>	2 <i>0.3</i>	0 <i>0.0</i>	0 <i>0.0</i>	20 <i>0.4</i>	
Esophageal atresia/tracheoesophageal fistula	72 <i>2.6</i>	21 <i>2.0</i>	11 <i>1.7</i>	7 <i>2.2</i>	0 <i>0.0</i>	112 <i>2.2</i>	
Gastroschisis	83 <i>3.0</i>	26 <i>2.4</i>	19 <i>2.9</i>	8 <i>2.5</i>	1 <i>11.4</i>	143 <i>2.8</i>	
Holoprosencephaly	61 <i>2.2</i>	36 <i>3.4</i>	16 <i>2.4</i>	1 <i>0.3</i>	0 <i>0.0</i>	117 <i>2.3</i>	
Hypoplastic left heart syndrome	76 <i>2.7</i>	37 <i>3.5</i>	20 <i>3.0</i>	6 <i>1.8</i>	1 <i>11.4</i>	145 <i>2.9</i>	
Hypospadias	817 <i>57.0</i>	312 <i>57.7</i>	85 <i>25.3</i>	70 <i>42.2</i>	3 <i>67.3</i>	1,333 <i>51.8</i>	1
Interrupted aortic arch	47 <i>1.7</i>	29 <i>2.7</i>	9 <i>1.4</i>	3 <i>0.9</i>	1 <i>11.4</i>	94 <i>1.9</i>	

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Defect	Maternal Race/Ethnicity					Total*	Notes
	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic		
Limb deficiencies (reduction defects)	76 2.7	34 3.2	15 2.3	4 1.2	0 0.0	133 2.6	
Omphalocele	43 1.5	53 5.0	9 1.4	9 2.8	0 0.0	118 2.3	
Pulmonary valve atresia and stenosis	123 4.4	82 7.7	36 5.5	13 4.0	0 0.0	262 5.2	
Pulmonary valve atresia	14 0.5	8 0.7	5 0.8	0 0.0	0 0.0	29 0.6	
Rectal and large intestinal atresia/stenosis	95 3.4	56 5.2	29 4.4	9 2.8	0 0.0	198 3.9	
Renal agenesis/hypoplasia	123 4.4	54 5.1	30 4.5	7 2.2	0 0.0	220 4.4	
Single ventricle	37 1.3	17 1.6	12 1.8	2 0.6	0 0.0	73 1.4	
Small intestinal atresia/stenosis	94 3.4	43 4.0	27 4.1	10 3.1	0 0.0	188 3.7	
Spina bifida without anencephalus	56 2.0	23 2.2	16 2.4	4 1.2	0 0.0	105 2.1	
Tetralogy of Fallot	111 4.0	57 5.3	21 3.2	17 5.2	0 0.0	215 4.3	
Total anomalous pulmonary venous connection	19 0.7	13 1.2	15 2.3	5 1.5	0 0.0	54 1.1	
Transposition of the great arteries (TGA)	68 2.4	32 3.0	21 3.2	9 2.8	1 11.4	133 2.6	
Dextro-transposition of great arteries (d-TGA)	63 2.3	32 3.0	20 3.0	9 2.8	1 11.4	127 2.5	
Tricuspid valve atresia and stenosis	33 1.2	14 1.3	7 1.1	2 0.6	0 0.0	59 1.2	
Trisomy 13	15 0.5	8 0.7	5 0.8	0 0.0	0 0.0	29 0.6	
Trisomy 18	39 1.4	17 1.6	10 1.5	4 1.2	0 0.0	72 1.4	
Trisomy 21 (Down syndrome)	338 12.1	104 9.7	137 20.7	22 6.8	1 11.4	626 12.4	
Turner syndrome	25 1.8	6 1.1	9 2.8	1 0.6	0 0.0	42 1.7	2
Ventricular septal defect	1,161 41.5	523 49.0	364 55.1	130 40.0	2 22.8	2,275 45.2	
Total live births	279,665	106,745	66,026	32,474	876	503,868	3
Male live births	143,444	54,119	33,635	16,592	446	257,442	
Female live births	136,217	52,622	32,387	15,878	430	246,408	

Virginia
Birth Defects Counts and Prevalence 2014 - 2018 (Prevalence per 10,000 Live Births)

Defect	Maternal Age (Years)		Total*	Notes
	Less than 35	35+		
Gastroschisis	141 <i>3.5</i>	2 <i>0.2</i>	143 <i>2.8</i>	
Trisomy 13	15 <i>0.4</i>	14 <i>1.5</i>	29 <i>0.6</i>	
Trisomy 18	37 <i>0.9</i>	35 <i>3.7</i>	72 <i>1.4</i>	
Trisomy 21 (Down syndrome)	296 <i>7.2</i>	330 <i>34.5</i>	626 <i>12.4</i>	
Total live births	408,332	95,536	503,868	3

Notes

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

General comments

*Data for totals include unknown and/or other.

-Data for conditions include probable/possible diagnoses.