

West Virginia

West Virginia Birth Defects Surveillance System

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

Partner: Hospitals, Universities, Early Childhood Prevention Programs

Program status: Currently collecting data

Start year: 1989

Earliest year of available data: 1989

Organizational location: Department of Health (Maternal and Child Health)

Population covered annually: 18,000

Statewide: Yes

Current legislation or rule: WV State Code 16-5-12a

Legislation year enacted: 1991; updated 2002

Case Definition

Outcomes covered: ICD-10 Codes Q00–Q07, Q10–Q18, Q20–Q28, Q30–Q34, Q35–Q37, Q38–Q45, Q50–Q56, Q60–Q64, Q65–Q79, Q80–Q89, Q90–Q99

Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

Age: 0-6 years

Residence: In-state births to state residents

Surveillance Methods

Case ascertainment: Passive case-finding without 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, Infant and Maternal Mortality Review Panel

Delivery hospitals: Discharge summaries

Pediatric & tertiary care hospitals: Discharge summaries

Other sources: Pediatric referrals

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 chart with a selected list of ICD-9-CM codes outside 740-759/ICD-10-CM codes outside 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), Infants with low birth weight or low gestation (<2500 grams or <37 weeks), All stillborn infants, All neonatal deaths, All infants in NICU or special care nursery

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, Developmental delay, GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Auditory/hearing conditions, 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.), Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.)

Data Collection Methods and Storage

Data collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

Database collection and storage: Access

Data Analysis

Data analysis software: Access

Quality assurance: Comparison/verification between multiple data sources, Timeliness

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiological studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration

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

Funding

Funding source: 100% MCH funds

Other

Web site: <http://wvdhhr.org/omcfh>

Additional information on file: Legislative reports on file with State Legislative Library

Contacts

Kathy Cummons, MSW

Research, Evaluation and Planning Division

350 Capitol St. Room 427

Charleston, WV 25301

Phone: 304-558-5388

Fax: 304-558-3510

Email: kathy.g.cummons@wv.gov

Melissa A. Baker, MA

Office of Maternal, Child and Family Health

350 Capitol St. Room 427

Charleston, WV 25301

Phone: 304-558-5388

Fax: 304-558-3510

Email: melissa.a.baker@wv.gov