### Montana

#### Birth Defects Surveillance System

<table>
<thead>
<tr>
<th>State</th>
<th>Statute/Rule</th>
<th>Language Specific to Surveillance System</th>
<th>Data Sharing</th>
<th>Research Authority</th>
<th>Consent Required?</th>
<th>Dissent Allowed?</th>
</tr>
</thead>
</table>

“Montana's economic situation is similar to that of the other states: a decline in state revenue has resulted in budget cuts for programs allocated state general dollars. The decline in state general revenue as well as the loss of federal funding to support programs (such as the coordinated school health program, the birth defects registry from CDC, the oral health program from HRSA, and the fetal alcohol spectrum disorder prevention program funding from SAMHSA) contributed to diminished FCHB staff and a subsequent reorganization. In May, 2010 the Infant Child Maternal Health Section was combined with the Maternal Child Health Coordination Section, decreasing the number of supervisory staff by one.” (p. 19)

“The Newborn Hearing and Metabolic Screening Program and the Birth Defects Registry was moved to the CSHS section in spring of 2006, in order to promote and coordinate clinical follow up and tracking. CSHS continues to support the development of Children's Health Referral and Information System (CHRIS), a data collection system that is interconnected.
with the RPSC, MT School for the Deaf and Blind, the MT Medical Genetics program, Healthy MT Kids, Social Security Disability, neonatal intensive-care unit (NICU) referrals, outreach specialty providers and others.” (p. 21)

“2012/Denise Higgins, BS-- Bureau Chief. Ms. Higgins has been the Bureau Chief of the FCHB since December of 2010. She holds BS is in Medical Technology from Illinois State University and is certified by the American Society of Clinical Pathologists. Ms. Higgins was the Newborn Screening & Serology Laboratory Manager for the Montana Public Health Laboratory at DPHHS. She was originally hired by the Montana Department of Public Health & Human Services to develop Montana's birth defects registry and conduct Newborn Screening follow-up. She has also coordinated laboratory bioterrorism activities and served as the Departments Planning Chief for the DPHHS Incident Command Team.” [all emphasis added]

From: “Public Health and Human Services,” 2/16/07, accessed 8/25/08:
“CSHS manages the birth defects registry. Montana’s birth defects registry application was approved, but not funded by CDC in 2005. The birth defects registry, which had begun active case ascertainment requiring medical records check for defined birth defects, moved to passive surveillance due to lack of funding. CSHS staff receives and tracks birth defects reported to them by health providers in Montana”

From: “State Title V Block Grant Narrative, State: Montana.”
Application Year: 2009,”
“DPHHS Environmental Public Health Tracking was established in 2004 with support from a 3-year grant from the CDC. EPHT's vision is to better protect communities from adverse health effects through the integration of public health and e nvironmental information, such as the Libby, Montana exposure. EPHT will improve surveillance of chronic diseases, birth defects, and developmental delays, and link health data with existing data on environmental hazards and exposures, to better inform the public regarding health concerns.”
“…CDC's State Health Profile for Montana notes childhood health concerns include birth defects, vaccination coverage, infant mortality, prenatal care, and teen pregnancy. Montana has developed a birth defects registry that now contains data for 2000 through 2004.”
“The MCHDM section houses Montana's birth defects registry, the Montana Birth Outcome Monitoring System (MBOMS), which was initiated with CDC funding in 2000. The population-based registry identifies and refers children in need of services to the CSHCN and other appropriate services. Initially, the program was a passive case ascertainment system, focusing on four major anomalies - congenital hypothyroidism and cleft-craniofacial, cardiac, and neural tube defects. CDC recommended active case ascertainment, which was added in 2001. The program was funded for an additional three years of CDC funding in 2002. A renewal application submitted in early 2005 was reviewed, approved, but not funded, leaving the future of the registry in question. At present, the registry, including the
active case ascertainment will be continued with carry over dollars, supplemented as possible with MCHBG. The long-range feasibility of continuing this support continues to be in question, especially in view of the MCHBG decreases over the last several years. Birth defect monitoring efforts continue with grant carryover and MCHBG funding at this time -- partnerships with the state's Environmental Public Health Tracking program are being explored. The registry has helped identify and inform investigations of what appeared to be high instances of Down Syndrome and gastroschisis in Montana over the last several years. The gastroschisis investigation continues with the help of student efforts from the Rollins School of Public Health at Emory University.” [emphasis added]