Missouri

**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>
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| MO    | NO STATUTE OR RULE FOUND | From: MO Dept of Health & Senior Services website, 2012: 
The Department of Health and Senior Services (DHSS) maintains a birth defects registry for Missouri resident live births based on linkage of defects reported on birth certificates, death certificates, hospital patient abstracts, enrollment data for state programs to assist affected families, such as the Hope program (formerly Children with Special Health Care Needs); and screening data such as the newborn hearing screening data set. Cases include defects diagnosed and reported through the first year of life. The registry includes data for all births in the state, but is not complete for some counties in which a substantial proportion of residents use out-of-state hospitals. While birth and death certificates are available for Missouri residents using out-of-state hospitals, DHSS has limited access to patient abstract data from these hospitals. Births since 1980 are included in the data set. | See “Research Authorized” | From: “Microcephaly: An epidemiologic analysis”, AJOG, June 2003: 
In 2003, the results of a study on microcephaly were reported to the 69th Annual meeting of the Central Association of Obstetricians and Gynecologists. The study used the Missouri | NO | NO |
Because of changes in access to data sets, and changes in data items included in each component data source, there are inconsistencies over time. For most investigations, DHSS prefers to limit studies to births since 1993. The data for a calendar year of births are generally available 20 months after the close of the year. The delay is necessary because cases are ascertained through the first year of life. Birth defect registry data are used to monitor the health status of Missourians, particularly in areas potentially affected by environmental contamination. The data are also used to assist public health and educational officials in the development and conduct of programs to assist affected families, and to assist families in gaining access to state services.

http://health.mo.gov/data/birthdefectsregistry/

From: Missouri Birth Defects 1996-2000” MO Dept. of Health and Senior Services, August 2003:

“The Missouri Department of Health and Senior Services (DHSS) established the birth defects registry to monitor the incidence of birth defects among Missouri infants, to provide data for epidemiological studies, surveillance for potential effects of environmental contamination, and to support and evaluate state programs serving ill and

| Birth Defects Registry to “identify 360 microcephaly cases and 3600 control cases during 1993 through 1999” |  |  |
disabled children. Data are available for births since 1980, but improvements in the data set make data for births since 1993 much more complete than data for earlier years (Appendix A). In 1998, DHSS was awarded a cooperative agreement with the Centers for Disease Control and Prevention (CDC), which enabled DHSS to improve the timeliness of its data and to use registry data to improve access to state-provided services.

Data presented in this report are for liveborn Missouri residents. Defects must be diagnosed in the first year of life in order to be included in the registry. The registry is a data collection effort in which data available from a number of sources are merged. Data sources currently available are birth certificates, infant death certificates, newborn patient abstracts, pediatric patient inpatient and outpatient abstracts, the DHSS data base for children enrolled in programs such as Children with Special Health Care Needs, and the Department of Mental Health First Steps (early intervention) data base. Defects reported in each component are linked to the birth certificate to avoid duplication. The birth certificate also provides important demographic data not available in most of the individual components and provides a basis for producing rates and comparing attributes of infants with and without birth defects.
The Missouri birth defects registry is a passive data collection system; case finding is limited to reports provided to DHSS from the sources listed above, and verification of reported defects is not undertaken. It is probable that some Missouri infants have birth defects diagnosed in the first year of life that are not reported on any of the data components and are not, therefore, included in the registry;”

From: *Southern Legislative Conference Question of the Month, Feb 2007*:
The Registry is funded: [federal] MCH Funds – 37%, Service Fees – 54%, Private Foundations – 9%