



MISSISSIPPI STATE DEPARTMENT OF HEALTH

## Mississippi Birth Defects Surveillance Registry Fact Sheet

<p>What is the Mississippi law pertaining to birth defects?</p>	<p>Section 41-21-205 of the Mississippi Code established a birth defects surveillance registry in the Mississippi State Department of Health. The law authorizes the Mississippi State Department of Health to adopt rules to govern the operation of the registry program. The Department of Health specifies the type of information to be provided to the birth defects registry and the persons and entities who are required to provide such information to the Birth Defects Surveillance Registry.</p>
<p>Who should report to the Birth Defects Surveillance Registry?</p>	<p>All hospitals, clinics, and other health facility personnel that serve patients (newborn to 21 years of age) should report to the Mississippi Birth Defects Surveillance Registry. The physician must report every birth defect case the first time the patient is seen for individuals born on or after January 1, 2000.</p>
<p>What are birth defects?</p>	<p>Birth defects are an abnormality of structure, function, or metabolism whether genetically caused or a result of outside factors during a child's developmental or fetal life. A birth defect may be present from the time of conception or birth, or may become evident later in the child's life.</p>
<p>How common are birth defects?</p>	<p>According to the Centers for Disease Control and Prevention (CDC), birth defects affect 1 in 33 babies and are a leading cause of infant mortality in the United States.</p>
<p>What are the causes of birth defects?</p>	<p>The causes for many birth defects are uncertain. However, environmental factors, medications, diet habits and personal behaviors have been identified as possible contributors to these defects. While much is still unknown concerning the causes of birth defects, there is a growing amount of information regarding the measures that can be used to prevent them.</p>
<p>What are the objectives of the Birth Defects Surveillance Registry?</p>	<ul style="list-style-type: none"> <li>• To monitor, regularly and systematically, the births of children with defects for changes in incidence or other unusual patterns suggesting preventable causes.</li> <li>• To ensure that children identified with birth defects are referred to services and their health and developmental outcomes are assessed periodically.</li> <li>• To increase reporting to the registry to ensure long term follow up and delivery of services.</li> </ul>
<p>What is the focus for the Birth Defects Surveillance Registry?</p>	<p>The Birth Defects Surveillance Registry focuses primarily on collecting information on live births and stillbirths in the state. Monitoring of birth defects require additional data to be collected (Active Surveillance).</p>
<p>How to receive a copy of the birth defects reporting form?</p>	<p>To receive a copy of the Reporting Form (272) please contact:          Mississippi State Department of Health          Genetic Services/Birth Defects Surveillance Registry          P.O. Box 1700          Jackson, MS 39215          Phone: 601-576-7619 Fax: 601-576-7498          Or visit <a href="http://www.healthymississippi.gov/BirthDefectsRegistry">www.healthymississippi.gov/BirthDefectsRegistry</a></p>
<p>How to submit monthly reports?</p>	<p>Complete monthly reports and submit to the aforementioned address. If there are multiple patients with birth defects (greater than 10) please contact the program to determine the best way to report. If there are no birth defects cases to report, please write no birth defects to report for the month (example: No birth defects for January 2017) with name of hospital/clinic and contact information on Reporting Form (272).</p>

## Active Birth Defects Surveillance Frequently Asked Questions

### What is Active Birth Defects Surveillance and why is it needed?

An approach to case identification based on finding and confirming potential birth defects cases through data sources and systematic investigations of pertinent sources of information to identify potential cases of birth defects. Data collection sites include hospital medical records, diagnostic indices, unit logs, pathology departments, and specialty sites. The purpose is rapid (real-time) population based surveillance of birth defects.

### What will be needed for Active Birth Defects Surveillance?

There is very specific information that is needed and will require direct access to medical records in order to complete forms in their entirety. These abstractions will need to be conducted weekly, or biweekly, on infants that meet case inclusion criteria. While the aforementioned method is preferable, if your facility is unable to provide direct access to these medical records, the department of health will place weekly calls in order to have the information sent.

### What are the Birth Defects of Interest for Active Surveillance?

<i>Brain abnormalities with or without microcephaly</i>	<i>Neural tube defects and other early brain malformations</i>	<i>Eye abnormalities</i>	<i>Consequences of central nervous system (CNS) dysfunction</i>
<ul style="list-style-type: none"> <li>• Microcephaly</li> <li>• Intracranial calcifications</li> <li>• Cerebral atrophy</li> <li>• Abnormal cortical formation (i.e. Polymicrogyria, lissencephaly, pachygyria, schizencephaly, gray matter heterotopia)</li> <li>• Corpus callosum abnormalities</li> <li>• Porencephaly</li> <li>• Hydranencephaly</li> <li>• Ventriculomegaly/hydrocephaly (excluding "mild" ventriculomegaly without other brain abnormalities)</li> <li>• Fetal brain disruption sequence (collapsed skull overlapping sutures prominent occipital bone, scalp ruggae)</li> <li>• Other major brain abnormalities including intraventricular hemorrhage in utero (excluding postnatal ivh)</li> </ul>	<ul style="list-style-type: none"> <li>• Neural tube defects (NTD)</li> <li>• Anencephaly/acrania</li> <li>• Encephalocele</li> <li>• Spina bifida and holoprosencephaly/arhinencephaly</li> </ul>	<ul style="list-style-type: none"> <li>• Microphthalmia/anophthalmia</li> <li>• Coloboma</li> <li>• Cataract</li> <li>• Intraocular calcifications</li> <li>• Chorioretinal anomalies involving the macula (i.e. chorioretinal atrophy and scarring, macular pallor, gross pigmentary mottling and retinal hemorrhage), excluding retinopathy or prematurity</li> <li>• Optic nerve atrophy</li> <li>• Pallor</li> <li>• Other optic nerve abnormalities</li> </ul>	<ul style="list-style-type: none"> <li>• Congenital contractures (arthrogryposis, club foot, congenital hip dysplasia) with associated brain abnormalities</li> <li>• Congenital deafness documented by postnatal testing</li> </ul>

### How will birth defects surveillance be enhanced and what can I expect?

Birth Defects Registry staff will place weekly or biweekly calls to all birthing facilities to determine if there are any infants born that meet case inclusion criteria. If there are births that meet the inclusion criteria, the BDR staff will provide a date and time to visit the facility to abstract and collect data from medical records.

### What will need to be provided?

Once permission to access medical records has been granted, if computer access is provided, the abstractor will need a computer to access the records in a private area in order to document case findings.

### How do I find more information about active surveillance?

Contact Genetic Services Bureau for more information at 601-576-7619.