

Alabama

Birth Defects Surveillance System

State	Statute/Rule	Language Specific to Surveillance System	Data Sharing	Research Authority	Consent Required?	Dissent Allowed?
AL	<p>GENERAL STATUTE: Code of Alabama, Title 22, Section 22-10A-2 (per NBDPN, http://www.nbdpn.org/current/resources/sgm/appendix2-2.pdf, 6/04)</p> <p>NO RULE FOUND</p>	<p>Section 22-10A-2 Diagnostic facilities, genetic counseling and prenatal testing for genetic disorders at University of Alabama in Birmingham and University of South Alabama.</p> <p>(a) The University of Alabama in Birmingham, through its laboratory of medical genetics, and the University of South Alabama shall expand their respective medical genetics programs to provide diagnostic facilities, genetic counseling and prenatal testing for genetic disorders.</p>	<p>Section 22-10A-2 ...</p> <p>(c) Each shall expand its current program to assist private physicians and clinics of the Department of Public Health, the State Crippled Children's Service and the Department of Mental Health and Mental Retardation in referring affected members and their families to the program.</p> <p>(d) Each shall <i>extend prenatal testing</i> to those families meeting criteria for eligibility, including but not limited to the following:</p> <p>(1) Pregnant women 35 years of age or older.</p> <p>(2) Pregnant women having had a previous Down's Syndrome child or a child with any other chromosomal disorder.</p>	NONE FOUND	NO	NO

*CCHF REPORT 2013: Patient Privacy and Public Trust:
How Health Surveillance Systems Are Undermining Both*

		<p>(b) Each shall:</p> <p>(1) Develop an education program designed to educate physicians and the public concerning genetic disorders and the availability of this program.</p> <p>(2) <i>Assure that genetic counseling is available to those Alabama families who need it. This will include those families who have a member with a birth defect, mental retardation, or other handicapping disorder due to genetic factors as well as families identified by screening to be at increased risk for having a child with one of these problems.</i></p> <p>(3) Formulate a graduated fee schedule, based on the ability of the patient to pay, to offset the costs of the program. <i>[emphasis added]</i></p>	<p>(3) Pregnancies where one parent is a translocation carrier.</p> <p>(4) Women who are carriers of an X-linked disorder.</p> <p>(5) Pregnancies where both parents are carriers of an Autosomal Recessive Disorder that can be detected prenatally.</p> <p>(6) Pregnancies where the parents have a previous child who has a neural tube defect. <i>[emphasis added]</i></p>			
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