

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>(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>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> <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>	NONE FOUND	NO	NO

Cancer Surveillance System

State	Statute/Rule	Language Specific to Surveillance System	Data Sharing	Research Authority	Consent Required?
AL	<p>STATUTE: Code of Alabama, Article 2, Sections 22-13-30 – 22-13-35</p> <p>RULE: Alabama Administrative Code, Chapter 420-7-3</p>	<p>Section 22-13-30 — Short title. This article shall be known and may be cited as the "Alabama Statewide Cancer Registry Act."</p> <p>Section 22-13-31 — Registry established; reporting of confirmed cases. (a) There is hereby established within the Department of Public Health the Alabama Statewide Cancer Registry for the purpose of providing accurate and up-to-date information about cancer or benign brain-related tumors in Alabama and facilitating the evaluation and improvement of cancer or benign brain-related tumor prevention, screening, diagnosis, therapy, rehabilitation, and community care activities for the citizens of Alabama. The State Committee of Public Health shall adopt rules necessary to affect the purposes of this article, including the data to be reported, and the effective date after which reporting shall be required. For the purposes of this article, cancer means all malignant neoplasms, regardless of the tissue of origin, including malignant lymphoma, Hodgkin's disease, and leukemia, but excluding basal cell and squamous cell carcinoma of the skin and carcinoma in situ of the cervix.</p>	<p>Section 22-13-31 Registry established</p> <p>(b) All cases of confirmed cancer or benign brain-related tumor diagnosed or treated in the state are to be reported to the State Health Department. For the purposes of this article, confirmed cancer or benign brain-related tumor means the best evidence available for determining the nature of the neoplasms.</p> <p>(c) The State Health Officer shall establish a training program to include instruction on the manner in which data are to be reported and shall be available to personnel of all reporting sources. A quality control program for cancer data shall be instituted to ensure the quality of data submitted.</p> <p>Section 22-13-34 — State Health Officer authorized to enter into agreements to exchange confidential information with other cancer registries and to furnish confidential information to other states, cancer registries, etc.</p> <p>(a) The State Health Officer may enter into agreements to exchange confidential information with other cancer registries to obtain complete reports of Alabama residents diagnosed or treated in other states and to provide information to other states regarding their residents diagnosed or treated in Alabama. (b) The State Health Officer may furnish confidential information to other states' cancer registries, federal cancer control agencies, or health researchers in order to collaborate in a national cancer registry or to collaborate in cancer control and prevention research studies.</p> <p>420-7-3-.05 Confidentiality Of Data. (7) Patient-specific data may be exchanged with any other cancer control agency or clinical facility for the purpose of obtaining information necessary to complete a case record. This data shall not be further disclosed by that agency or clinical facility. (8) Follow-up information which is not available from the healthcare facility or provider may be obtained by the ASCR. The healthcare facility/provider may obtain follow-up information from the ASCR.</p>	<p>Section 22-13-33 ... (c) Cancer or benign brain-related tumor information may be provided to researchers or research institutions, or both, in connection with cancer or benign brain-related tumor morbidity and mortality studies upon appropriate review by the State Health Officer.</p> <p>Section 22-13-35 – Liability Under Article. (a) No person shall have any claim or cause of action against the State of Alabama, or its political subdivisions, or any individual arising out of any acts or omissions which occurred under the provisions of this article, if the state, political subdivisions or individual is in compliance with this article.</p> <p>(b) No person shall have any claim or cause of action against any person, or the employer or employee of any person, who participates in good faith in the reporting or receiving, or both, of cancer registry data or data for cancer or benign brain-related tumor morbidity or mortality studies in accordance with this article. (c) No license of a health care facility or health care provider may be denied, suspended, or revoked for the good faith disclosure of confidential or privileged information in the reporting of cancer registry data or data for cancer or benign brain-related tumor morbidity or mortality studies in accordance with this article.</p>	NO

			<p>Section 22-13-35 — Liability under article. (a) No person shall have any claim or cause of action against the State of Alabama, or its political subdivisions, or any individual arising out of any acts or omissions which occurred under the provisions of this article, if the state, political subdivisions or individual is in compliance with this article. (b) No person shall have any claim or cause of action against any person, or the employer or employee of any person, who participates in good faith in the reporting or receiving, or both, of cancer registry data or data for cancer or benign brain-related tumor morbidity or mortality studies in accordance with this article...(c) No license of a health care facility or health care provider may be denied, suspended, or revoked for the good faith disclosure of confidential or privileged information in the reporting of cancer registry data or data for cancer or benign brain-related tumor morbidity or mortality studies in accordance with this article. (d) No license of a health care facility or health care provider may be denied, suspended, or revoked for the failure to disclose confidential or privileged information in the reporting of cancer or benign brain-related tumor registry data or data for cancer or benign brain-related tumor morbidity or mortality studies. (e) Nothing in this article shall be construed to apply to the unauthorized disclosure of confidential or privileged information when that disclosure is due to gross negligence or wanton or willful misconduct.</p>	<p>(d) No license of a health care facility or health care provider may be denied, suspended, or revoked for the failure to disclose confidential or privileged information in the reporting of cancer or benign brain-related tumor registry data or data for cancer or benign brain-related tumor morbidity or mortality studies.</p> <p>420-7-3-.05 Confidentiality Of Data. (3)... (a) Information may be disclosed as provided in the Access to Information for Research Purposes of these Rules</p> <p>420-7-3-.06 Access To Information For Research Purposes. (1) The ASCR may release statistical data only to any person or agency for the following purposes: (a) medical research or education; (b) epidemiologic studies; (c) health education; (d) health planning or administration; (e) required statistical reports necessary for publication of an annual report; (f) publication of the ASCR annual report; and (g) other statistical reports not previously produced and/or published by written request for research, information or education.</p>	
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Newborn Genetic Testing & Surveillance System

State	Statute/ Rule	Language Specific to Genetic Testing and Surveillance System	Exemption	Research Authority	Consent Required?	Dissent Allowed?
AL	<p>STATUTE: Code of Alabama, Title 1, Article 8</p> <p>RULE: A.A.C., Chapter 420-10-1</p>	<p>Section 22-20-3 — Neonatal testing for certain diseases; rules and regulations for treatment thereof.</p> <p>(a) It shall be the duty of the administrative officer or other persons in charge of each institution caring for infants 28 days or less of age, or the physician attending a newborn child or the person attending a newborn child that was not attended by a physician to cause to have administered to every such infant or child in his care a reliable test for hypothyroidism and a reliable test for phenylketonuria (PKU), such as the Guthrie test, or any other test considered equally reliable by the State Board of Health and a reliable test for sickle cell anemia, sickle cell trait, and/or abnormal hemoglobin and <i>such other tests relating to mental retardation or other heritable diseases and conditions as are designated by the Board of Health</i>. Provided, however, that the Board of Health shall designate only conditions that are detectable by mass screening of newborn infants. Initial mass screening tests and the recording of results shall be performed by the Public Health Laboratory at such times and in such manner as may be prescribed by the State Board of Health; confirmatory tests shall be undertaken by such laboratory facilities as are designated by the attending physician or parent; ... <i>[emphasis added]</i>(b) The State Board of Health shall promulgate such rules and regulations as it considers necessary to provide for the care and treatment of those newborn infants whose tests are determined positive, including but not limited to, advising dietary treatment for such infants. The State Board of Health shall promulgate any other rules and regulations necessary to effectuate the provisions of this section including the collection of a reasonable fee for the newborn child screening program.</p> <p>420-10-.04 Reporting and Notification (1) The Alabama Department of Public Health shall report all results of ... testing to the submitting health care provider...(2) The submitting health care provider shall report all results, including positives, suspected positive results, and unsatisfactory specimens, to the physician of record...(3) The Department of Public Health may release results of newborn screening tests, including hearing screening results, to any physician registered with the Alabama Voice Response System under the terms and conditions of the system without a signed release form the parent or guardian.</p>	<p>Section 22-20-3</p> <p>(a) ... <i>provided</i>, that no such initial screening or confirmatory tests shall be given to any child whose parents object thereto on the grounds that such tests conflict with their religious tenets and practices. In the event a test is not given to a child on account of such objections by the parents, then no physician, nurse, laboratory technician, person administering tests, hospital, institution or other health care provider shall be liable for failure to administer the test.</p> <p>NOTE: The Department's Rule does not mention the right of parents to object to the testing or provide a method for parents to secure that exemption.</p>	NONE FOUND	NO	YES

Vaccination Surveillance System

State	Statute/ Rule	Language Specific to Surveillance System	Exemption	Data Sharing	Consent Required?	Dissent Allowed?
AL	<p>STATUTE: Code of Alabama, Section 22-11B-1 to 22-11B-4</p> <p>RULE: A.A.C. Chapter 420-6-2</p>	<p>Section 22-11B-1 — Health care providers upon request required to give immunization status of patients. (a) Notwithstanding any of the confidentiality provisions in Chapter 11A of this title, or any other provisions of law, every public and private health care provider shall, upon request of the persons or entities herein identified, provide information concerning the immunization status of any patient in accordance with rules promulgated by the State Board of Health...</p> <p>Section 22-11B-2 — Immunization registry. Pursuant to and in furtherance of the purposes of this chapter, the State Board of Health is authorized to create and maintain an immunization registry. The immunization registry is the central collection of data and reports concerning a vaccine dose or doses administered to a person by a provider. The nature of the immunization information contained in this registry shall be determined by rule of the State Board of Health and shall be obtained from clinic records, billing data and information, and vital or any other records owned and controlled by the State Board of Health and the Alabama Medicaid Agency. Medical insurers and public and private providers are authorized and encouraged to provide information to the registry.</p> <p>420-6-2-.01 Definitions... (3) Immunization registry means the statewide, centralized computerized database created, owned, and maintained by the department and which contains immunization information consisting of identifying, locating, and immunization data about former or current Alabama residents.</p>	<p>420-6-2-.03 Exchange Of Immunization Information... (5) Health care providers are strongly encouraged to submit data to the immunization registry, and immunization data users are strongly encouraged to access the immunization registry as a preferred means to exchange immunization data.</p>	<p>Section 22-11B-4 — Limited immunity of person or entity providing information. All persons, firms, corporations, or other public or private entities and all officers, agents, servants, or employees who provide information for exchange in good faith pursuant to this chapter shall be immune from civil and criminal liability for those actions and no cause of action shall be created by their acts or omissions hereunder.</p> <p>420-6-2-.04 Access To The Immunization Registry... (3) By memoranda of understanding, the department may permit electronic access to the immunization registry via computer systems operated by other immunization data users.</p> <p>420-6-2-.06 Permitted Uses Of The Immunization Registry... (5) The department may conduct surveys to identify children and geographic areas that represent underserved areas of need. Researchers may submit proposals to receive immunization registry data, but such provided data shall not identify individual patients, health care providers, or health care insurers. Data may be provided in the form of paper reports and summaries or electronic files. The department will establish procedures to evaluate the suitability of research proposals. The department will consider such requests in light of its capacity and resources to respond.</p>	NO	NO

