## Arkansas

### Newborn Genetic Testing & Surveillance System

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<tr>
<th>State</th>
<th>Statute/Rule</th>
<th>Language Specific to Genetic Testing and Surveillance System</th>
<th>Exemption</th>
<th>Research Authority</th>
<th>Consent Required?</th>
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| AR    | STATUTE: A.C.A., Title 20, Subtitle 2, Chapter 15, Subchapter 3  
 Rule: AAC, 007.16.07-001 | **20-15-301. Injunction.** The State Board of Health shall have the power to enforce this subchapter by appropriate action for injunction in the circuit courts of this state.  
**20-15-302. Testing of newborns.** (a)(1)(A) All newborn infants shall be tested for phenylketonuria, hypothyroidism, galactosemia, cystic fibrosis, and sickle-cell anemia. (B) In addition, if reliable and efficient testing techniques are available, all newborn infants shall be tested for other genetic disorders of metabolism by employing procedures approved by the State Board of Health…  
(b) All positive test results shall be sent immediately to the Division of Health of the Department of Health and Human Services. | **20-15-302.** (e) The provisions of this section shall not apply if the parents or legal guardian of a newborn infant object to the testing on medical, religious, or philosophical grounds. | **20-15-302 Testing of newborns.**  
(c)(2)(A) Information on newborn infants and their families compiled under this section may be used by the division and persons or public or private entities designated by the division.  
(B) Information used under subdivision (c)(2)(A) of this section may not refer to or disclose the identity of any person. | NO | YES |
### 007.16.07-001. Section I. Purpose.

The purpose of this regulation is to assure that all infants born in Arkansas have the opportunity to be screened for genetic metabolic illnesses…

#### (c)(1)
The division shall establish and maintain a program of reviewing and following up on positive cases so that measures may be taken to prevent mental retardation or other permanent disabilities.

#### (c)(3)
All materials, data, and information received by the division are confidential and are not subject to examination or disclosure as public information under the Freedom of Information Act of 1967, § 25-19-101 et seq.….  

### 20-35-103. Nondisclosure.

(b)(1) All stored tissues, including blood, that arise from surgery, other diagnostic or therapeutic steps, or autopsy may be disclosed for genetic or other research studies, if:

- **(A)** The patient’s name or social security number is not attached to or included with the specimen; or
- **(B)** The patient’s name or social security number is attached to or included with the specimen and the patient has given informed written consent to the disclosure.
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<th>Section VI. ARKANSAS DEPARTMENT OF HEALTH ROLE IN TREATMENT AND MONITORING</th>
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<td><strong>B. Registry</strong> 1. For Phenylketonuria (PKU), Congenital Hypothyroidism (CH), Galactosemia, Sickle Cell Disease (SS) and other hemoglobinopathies, Biotinidase Deficiency (BIOT), Congenital Adrenal Hyperplasia (CAH), Cystic Fibrosis (CF), Amino Acid Disorders, Fatty Acid Oxidation Disorders, or Organic Acid Disorders, the Department shall maintain a registry to record laboratory results and diagnoses of all tested infants, and to track referral for those infants in whom abnormal findings were noted during the screening process. <em>emphasis added</em></td>
<td>(2) Informed written consent shall not be included in a section of the consent for treatment, admission to a hospital or clinic, or permission for an autopsy.</td>
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<td>(c)(1) It shall be permissible to publish or otherwise use the results of genetic research studies for research or educational purposes if no individual subject is identified.</td>
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<td>(2) If specific informed consent from the individual has been obtained in writing, the individual may be identified.</td>
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