Confidentiality of information

The following states have laws covering this topic.

State statutes and regulations were accessed online in May 2015.

**Alaska**

Regulations:
Alaska Admin. Code

Title 7, Part 2, Chapter 27, Art. 16 Confidentiality, Authorized Uses, and Security Standards
Section 27.890. Confidentiality of required reports and medical records; applicability
(a) A report to the division required under this chapter and all information received by the department while exercising its authority under AS 18.05 or AS 18.15 are considered medically related public health records for purposes of AS 40.25.120(a)(3) and are not public information subject to the public records requirements of AS 40.25.110.
(b) All reports, information, and medically related public health records acquired by the department while exercising its authority under AS 18.05 or AS 18.15 are subject to the confidentiality and privacy safeguards in 7 AAC 27.890 - 7 AAC 27.899.

Title 7, Part 2, Chapter 27, Art. 16 Confidentiality, Authorized Uses, and Security Standards
Section 27.891. Identifiable health information
(a) All identifiable health information collected and maintained by the department under its authority in AS 18.05 or AS 18.15 shall be safeguarded as confidential and may only be acquired, used, and stored for a public health purpose and in a manner consistent with 7 AAC 27.890 - 7 AAC 27.899.

**Arizona**

Statutes:

Title 36, Chapt. 6, Art. 5 Maternal and Child Health
Section 36-694. Report of blood tests; newborn screening program; committee; fee; definitions
E. The newborn screening program shall establish and maintain a central database of newborns and infants who are
tested for hearing loss and congenital disorders that includes information required in rule. Test results are confidential subject to the disclosure provisions of sections 12-2801 and 12-2802.

Regulations:
Ariz. Admin. Code

Title 9, Chapt. 13, Art. 2 Newborn and Infant Screening
R9-13-206. Reporting Requirements for Specimens
D. Bloodspot test results are confidential subject to the disclosure provisions of 9 A.A.C. 1, Article 3, and A.R.S. §§12-2801 and 12-2802.

Other applicable statutes:

Title 12, Chapt. 19, Art. 1 Genetic Testing, General Provisions
Section 12-2801. Definitions
In this chapter, unless the context otherwise requires:
1. “Genetic test” or “genetic testing”:

(b) Does not include:
(v) Tests given for use in biomedical research that is conducted to generate scientific knowledge about genes or to learn about the genetic basis of disease or for developing pharmaceutical and other treatment of disease.

12-2802. Confidentiality of genetic testing results; disclosure
A. Except as otherwise provided in this article, genetic testing and information derived from genetic testing are confidential and considered privileged to the person tested and shall be released only to:

2. Any person who is specifically authorized in writing by the person tested or by that person's health care decision maker to receive this information.

4. A researcher for medical research or public health purposes only if the research is conducted pursuant to applicable federal or state laws and regulations governing clinical and biological research or if the identity of the individual providing the sample is not disclosed to the person collecting and conducting the research.

8. A health care provider to conduct utilization review, peer review and quality assurance pursuant to section 36-441, 36-445, 36-2402 or 36-2917.

9. The authorized agent of a federal, state or county health department to conduct activities specifically authorized pursuant to the laws of this state for the birth defects registry, children's rehabilitative services, newborn screening and sickle cell diagnosis and treatment programs and chronic, environmentally provoked and infectious disease programs.

B. A person shall not disclose or be compelled to disclose the identity of any person on whom a genetic test is performed or the results of a genetic test in a manner that allows identification of the person tested except to the persons specified in the circumstances set forth in subsection A of this section.

G. A health care provider and the provider's agents and employees that act in good faith and that comply with this article are not subject to civil liability. The good faith of a health care provider that complies with this article is presumed. The presumption may be rebutted by a preponderance of the evidence.

H. This article does not limit the effect of title 20 provisions governing the confidentiality and use of genetic testing information.
Arkansas

Statutes:
Ark. Code

Title 20, Subtitle 2, Chapt. 15, Subchapt. 3  Phenylketonuria, Hypothyroidism, and Sickle-Cell Anemia

.  .  .
(c) (2) (B) Information used under subdivision (c)(2)(A) of this section may not refer to or disclose the identity of any person.

(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.

California

Statutes:

Section 124975

.  .  .
(j)  .  .  . All information obtained from persons involved in hereditary disorders programs in the state should be held strictly confidential.

Section 124980

.  .  .
(j) All testing results and personal information from hereditary disorders programs obtained from any individual, or from specimens from any individual, shall be held confidential and be considered a confidential medical record except for information that the individual, parent, or guardian consents to be released, provided that the individual is first fully informed of the scope of the information requested to be released, of all of the risks, benefits, and purposes for the release, and of the identity of those to whom the information will be released or made available, except for data compiled without reference to the identity of any individual, and except for research purposes, provided that pursuant to Subpart A (commencing with Section 46.101) of Part 46 of Title 45 of the Code of Federal Regulations entitled "Basic HHS Policy for Protection of Human Subjects," the research has first been reviewed and approved by an institutional review board that certifies the approval to the custodian of the information and further certifies that in its judgment the information is of such potentially substantial public health value that modification of the requirement for legally effective prior informed consent of the individual is ethically justifiable.

Section 124991

.  .  .
(g) The department, any entities approved by the department, and researchers shall maintain the confidentiality of patient information and blood samples in accordance with existing law and in the same manner as other medical record information with patient identification that they possess, and shall use the information only for the following purposes:

(1) Research to identify risk factors for children's and women's diseases.
(2) Research to develop and evaluate screening tests.
(3) Research to develop and evaluate prevention strategies.
(4) Research to develop and evaluate treatments.
Regulations:

Title 17, Division 1, Chapt. 4, Subchapt. 9, Testing for Heritable Disorders
§ 6502.1. Confidentiality.
(a) All information, records of interview, written reports, statements, notes, memoranda, or other data procured by an individual, group or research team in the course of any testing under this Group shall be confidential and shall be used solely for the purposes of medical intervention, counseling, or specific research project approved by the Department.

Title 17, Division 1, Chapt. 4, Subchapt. 9, Testing for Heritable Disorders
§ 6504.6. Record Maintenance.
. . . All such information and records shall be confidential, but shall be open to examination by the Department personnel or its designated agents for any purpose directly connected with the administration of the newborn screening program.

Colorado

Statutes:

Title 25, Art. 4, Part 10 Newborn Screening and Genetic Counseling and Education Act
25-4-1002. Legislative declaration
(1) The general assembly hereby finds and declares that:
. . .
(b) Participation of persons in genetic counseling programs in this state should be wholly voluntary and that all information obtained from persons involved in such programs or in newborn screening programs in the state should be held strictly confidential.

Title 25, Art. 4, Part 10 Newborn Screening and Genetic Counseling and Education Act
25-4-1003. Powers and duties of executive director - newborn screening programs - genetic counseling and education programs - rules
. . .
(2) The executive director of the department of public health and environment shall comply with the following provisions:
. . .
(e) All information gathered by the department of public health and environment, or by other agencies, entities, and individuals conducting programs and projects on newborn screening and genetic counseling and education, other than statistical information and information which the individual allows to be released through his informed consent, shall be confidential. Public and private access to individual patient data shall be limited to data compiled without the individual's name.
**Delaware**

Regulations:
Del. Admin. Code

Title 16, Department of Health and Social Services Division of Public Health, Family Health Services, 4107 Screening of Newborn Infants for Metabolic, Hematologic, Endocrinologic, and Certain Structural Disorders

Section 9.0 Confidentiality of Records.
9.1 The Newborn Screening Program shall maintain and treat as confidential all newborn screening communications with facilities, families and health care providers. The Newborn Screening Program shall maintain and treat as confidential a record of every newborn in whom a diagnosis of one or more of the various metabolic, hematologic, or endocrinologic disorders is confirmed.

**District of Columbia**

Statutes:
D.C. Code

Title 7, Subtitle B, Chapt. 8 A. Newborn Screening
§ 7-834. Principles governing newborn screening
The Mayor shall insure that:

. . .
(3) . . . all information obtained from persons involved in metabolic disorder programs in the District of Columbia should be held strictly confidential, except as provided for in subparagraph (D) of this paragraph;

. . .
(D) Except for statistical data compiled without reference to the identity of any individual, all information obtained from any individual or from specimens from any newborn shall be held confidential and be considered a confidential medical record except for such information as the parent consents to be released. The parent must be informed of the scope of the information requested to be released and the purpose for releasing such information, prior to the release of any confidential information.

**Florida**

Statutes:
Fla. Stat.

Title XXIX Chapter 383 Maternal and Infant Health Care
383.14 Screening for metabolic disorders, other hereditary and congenital disorders, and environmental risk factors.

. . .
(3) Department of Health; Powers and Duties.— The department shall administer and provide certain services to implement the provisions of this section and shall:

. . .
(d) Maintain a confidential registry of cases, including information of importance for the purpose of followup services to prevent intellectual disabilities, to correct or ameliorate physical disabilities, and for epidemiologic studies, if indicated. Such registry shall be exempt from the provisions of s. 119.07(1).
**Hawaii**

Statutes:

Division 1, Title 19, Chapt. 321, Part XXII. Newborn Metabolic Screening
§ 321-291  Tests for phenylketonuria, hypothyroidism, and other metabolic diseases

(c) The department of health shall adopt rules pursuant to chapter 91, necessary for the purposes of this section, including, but not limited to:

(3) Retention of records and related data;

(7) Maintaining the confidentiality of affected families.

Regulations:
Haw. Admin. Rules

Title 11, Chapt. 143 Testing of Newborn Infants for Metabolic and Other Diseases
§ 11-143-12  Confidentiality. All information, including records, correspondence, and documents, specific to individual newborns, shall be confidential and shall be used solely for the purposes of medical intervention, counseling, scientific research, or reporting. The infant's name shall be kept confidential.

**Idaho**

Regulations:
Idaho Admin. Code

Dept Health and Welfare
16.02.12 - Procedures and Testing to be Performed on Newborn Infants

01. Confidential Records. Any information about an individual covered by these rules and contained in the Department's records must comply with IDAPA 16.05.01, "Use and Disclosure of Department Records."

**Illinois**

Regulations:
Ill. Admin. Code

Title 77, Chapt. I, Subchapt. I, Part 661 Newborn Metabolic Screening and Treatment
Section 661.50 Diagnosis and Treatment

The Department will maintain confidentiality at all times with regard to patient information.
**Indiana**

Regulations:
Ind. Admin. Code

Title 410, Art. 3. Maternal and Child Health
3-3-6 Maintenance of screening logs; follow-up of missing results; monthly reports as submitted by hospitals, birthing centers, midwives, and physicians providing home birth services

Sec. 6. (a) Each hospital or birthing center, and midwife or physician submitting screening tests on newborns or infants born outside a hospital or birthing center shall maintain a newborn screening log that shall contain the following:

1. Name of newborn or infant.
2. Attending physician or midwife.
3. Medical record number.
4. Form number of sample sent.
5. Date sample collected.
6. Date sample sent.
7. Date results received.
8. What the results were.
9. Name of person notified of positive results and date and time of notification.

All such information and records shall be confidential but shall be open to examination by the department personnel or its designated agents for any purpose directly connected with the administration of the newborn screening program.

Title 410, Art. 3. Maternal and Child Health
3-3-7 Follow-up of positive results, recommendations

Sec. 7.

(h) The department shall maintain the following:

1. A tracking system for follow-up of newborn screening results.
2. A confidential registry of every newborn or infant born for whom the diagnosis of:
   - phenylketonuria;
   - hypothyroidism;
   - galactosemia;
   - maple syrup urine disease;
   - homocystinuria;
   - hemoglobinopathy;
   - cystic fibrosis;
   - hearing loss; or
   - another metabolic or endocrine condition;

has been confirmed.

These records shall be utilized only for the purpose of service delivery and program administration and shall be managed in accordance with 410 IAC 21-3.

**Iowa**

Statutes:
Iowa Code

Title IV, Chapt. 136A  Center for Congenital and Inherited Disorders

§ 136A.3 Establishment of center for congenital and inherited disorders -- duties.
A center for congenital and inherited disorders is established within the department. The center shall do all of the following:

8. Participate in policy development to assure the appropriate use and confidentiality of genetic information and technologies to improve health and prevent disease.

Title IV, Chapt. 136A  Center for Congenital and Inherited Disorders
§ 136A.7 Confidentiality.
The center for congenital and inherited disorders and the department shall maintain the confidentiality of any identifying information collected, used, or maintained pursuant to this chapter in accordance with section 22.7, subsection 2.

Regulations:
Iowa Admin. Code

Public Health Dept [641] Chapt. 4  Center for Congenital and Inherited Disorders
Rule 641-4.3 (136A) Iowa newborn screening program (INSP).

4.3(1) Newborn screening policy.

4.3(7) Sharing of information and confidentiality. Reports, records, and other information collected by or provided to the Iowa newborn screening program relating to an infant's newborn screening results and follow-up information are confidential records pursuant to Iowa Code section 22.7(2).

4.7(5) Confidentiality and disclosure of information. Reports, records, and other information collected by or provided to the IRCID relating to a person known to have or suspected of having a congenital or inherited disorder are confidential records pursuant to Iowa Code sections 22.7 and 136A.7. INSP data may be retained indefinitely.

4.7(6) Access to information in the IRCID. The IRCID and the department shall not release confidential information except to the following, under the following conditions:

e. Researchers, in accordance with the following:

1. All proposals for research using the IRCID data to be conducted by persons other than program staff shall first be submitted to and accepted by the researcher's institutional review board. Proposals shall then be reviewed and approved by the department and the IRCID's internal advisory committee before research can commence.

2. The IRCID shall submit to the IRCID's internal advisory committee for approval a protocol describing any research conducted by the IRCID in which the IRCID deems it necessary to contact case subjects and controls.
**Louisiana**

Statutes:

Title 40 Public health and safety
§ 1299.6 Privacy of genetic information
With the exception of genetic tests specifically mandated to be reported by law, the results of any prenatal or postnatal genetic tests shall be confidential medical information and shall be excluded from reporting requirements. The results of such genetic tests shall become part of the medical record of the person tested and shall be confidential unless express written consent to their release is granted by the person tested.

**Maryland**

Statutes:
Ann. Code of Md.

Article – Health - General
§ 13-102. Findings

The General Assembly finds that:

(10) Participation in a hereditary and congenital disorders program should be wholly voluntary, and all information obtained about any individual in a hereditary and congenital disorders program should be kept confidential;

(11) A commission is needed:

(i) To ensure that the policies and programs of this State for hereditary and congenital disorders comply with the principles established in this subtitle; and

(ii) To preserve and protect the freedom, health, and well-being of the citizens of this State from improper treatment or advice, discrimination, violation of privacy, or undue anxiety that results from any hereditary and congenital disorders program.

Article – Health - General

(c) Minimum standards -- Access to information. --

(1) The rules, regulations, and standards of the Department shall require the Department and each person who conducts a hereditary and congenital disorders program to keep in code and treat as a confidential medical record all information that is gathered in the program and identifies an individual.

Regulations:
Code of Md. Regs.

Title 10, Subtitle 52, Chapt. 12 Newborn Screening
10.52.12.15 Records.
A. The screening of newborn infants pursuant to this chapter is a population based public health surveillance program.

C. Information that the Department receives under this chapter is confidential and may only be used or disclosed:

(2) To study the relationships of the various factors determining the frequency and distribution of the disorders set forth in Regulation .05 of this chapter;
**Massachusetts**

Regulations:

Title 105 CMR 27.000 Blood Screening of Newborns for Treatable Diseases and Disorders
Section 270.011: Confidentiality
The Newborn Blood Screening Program shall maintain the confidentiality of testing results and information submitted concerning follow-up of newborn testing and shall not disclose such results or any information or patient identifiers which because of name, identifying number, mark or description can be readily associated with a particular individual, except to that individual, anyone authorized in writing by that individual, authorized Department personnel, or any researcher authorized pursuant to M.G.L. c.111, § 24A for studies approved by the Department's Institutional Review Board. All individually identifiable testing results and information shall be considered confidential and shall not be available as a public record under M.G.L. c. 66.

**Michigan**

Statutes:
Mich. Comp. Laws

Chapt. 333, Act 368, Art. 5, Part 54 Chronic Diseases
Section 333.5431 Testing newborn infant for certain conditions; reporting positive test results to parents, guardian, or person in loco parentis; compliance; fee; "Detroit consumer price index" defined; violation as misdemeanor; hardship waiver; conduct of department regarding blood specimens; pamphlet; additional blood specimen for future identification. Sec. 5431.

(7) The department shall do all of the following in regard to the blood specimens taken for purposes of conducting the tests required under subsection (1):

(b) Allow the blood specimens to be used for medical research during the retention period established under subdivision (a), as long as the medical research is conducted in a manner that preserves the confidentiality of the test subjects and is consistent to protect human subjects from research risks under subpart A of part 46 of subchapter A of title 45 of the code of federal regulations.

**Minnesota**

Regulations:
Minn. Admin. Rules

Chapt. 4615 Maternal and Infant Health
4615.0760 Responsibilities of Department of Health.

Mississippi

Statutes:
Miss. Code Ann.

Title 41, Chapt. 21. Individuals With Mental Illness or an Intellectual Disability
Screening, Testing, and Investigation by State Board of Health
§ 41-21-205. Creation of Birth Defects Registry

(a) Data obtained under this section directly from the medical records of a patient is for the confidential use of the
department and the persons or public or private entities that the department determines are necessary to carry out the
intent of this section. The data is privileged and may not be divulged or made public in a manner that discloses the
identity of an individual whose medical records have been used for obtaining data under this section.

(b) Information that may identify an individual whose medical records have been used for obtaining data under this
section is not available for public inspection under the Mississippi Public Records Act of 1983.

Regulations:
Miss. Admin. Code

Title 15, Part 4, Subpart 1, Chapt. 1, Division of Genetics
Chapter 3. Identifying Reportable Cases
Rule 3.1.1. Definition of Birth Defect

3. Persons and Entities Required to Provide Information to the Registry

6. Confidentiality and Security
   a. Information collected and analyzed by the department under this section shall be placed in the central registry to
   facilitate epidemiological studies/reviews and to maintain security.
   i. Data obtained under this section directly from the medical records of a patient is for the confidential use of the
department and the persons or public or private entities that the department determines are necessary to carry out the
intent of this section. The data is privileged and may not be divulged or made public in a manner that discloses the
identity of an individual whose medical records have been used for obtaining data under this section.
   ii. Information that may identify an individual whose medical records have been used for obtaining data under this
   section is not available for public inspection under the Mississippi Public Records Act of 1993.

Missouri

Statutes:

Chapt. 191 Health and Welfare
Genetics and Metabolic Disease Programs
Section 191.323. Powers and duties of department of health and senior services in prevention and treatment of genetic
diseases and birth defects.
The department may:
(3) Conduct or support scientific research concerning the causes, mortality, methods of treatment, prevention and cure of genetic diseases which are considered to be of major importance to the problems of genetic disease and birth defects in Missouri, in cooperation with other public and private agencies, except as provided in section 188.037;

(4) Maintain a central registry to collect and store data to facilitate the compiling of statistical information on the causes, treatment, prevention and cure of genetic diseases. Identifying information shall remain confidential pursuant to the provisions of section 191.315. Information will be reported to the Missouri board of health and other health care agencies so that it may be used for the prevention and treatment of genetic diseases and birth defects;

Chapt. 191 Health and Welfare
Genetics and Metabolic Disease Programs

Section 191.317. Confidentiality of all tests and personal information -- exceptions -- retention of specimens, procedure.

1. All testing results and personal information obtained from any individual, or from specimens from any individual, shall be held confidential and be considered a confidential medical record, except for such information as the individual, parent or guardian consents to be released; but the individual must first be fully informed of the scope of the information requests to be released, of the risks, benefits and purposes for such release, and of the identity of those to whom the information will be released. Statistical data compiled without reference to the identity of any individual shall not be declared confidential. Notwithstanding any other provision of law to the contrary, the department may release the results of newborn screening tests to a child's health care professional.

Nevada

Regulations:
Nev. Admin. Code

Maternal and Child Health
442.060 Confidential records.

1. Except as otherwise provided in subsection 2 or required to carry out NRS 442.300 to 442.330, inclusive, and NAC 442.052 to 442.058, inclusive:
   (a) Any information concerning personal facts and circumstances obtained by the State or a local staff administering the program of services for maternal and child health and the care and treatment of children with special health care needs is a privileged communication and must be held confidential.

New Hampshire

Regulations:
N.H. Code Admin. Rules

Chapt. He-P 3000, Part He-P3008, Newborn Screening and Newborn Hearing Screening
Section He-P 3008.17 Confidentiality and Security of Records.
(a) All records maintained by the NSP and EHDI or its contractors, including paper files, facsimile transmissions, or electronic data transfers, shall be strictly confidential.
(b) All confidential information shall be kept in a secured area at all times as follows:
   (1) Paper records and external electronic storage media shall be kept in locked file cabinets;
   (2) All electronic files shall be password protected; and
   (3) All confidential notes or other materials that do not require storage shall be shredded immediately after use.
**New Jersey**

Statutes:

Title 26 Health and Vital Statistics
26:2-111. Testing of infants for biochemical disorders

Information on newborn infants and their families compiled pursuant to this section may be used by the department and agencies designated by the commissioner for the purposes of carrying out this act, but otherwise the information shall be confidential and not divulged or made public so as to disclose the identity of any person to which it relates, except as provided by law. The department shall conduct an intensive educational and training program among physicians, hospitals, public health nurses and the public concerning those biochemical disorders. This program shall include information concerning the nature of the disorders, testing for the detection of these disorders and treatment modalities for these disorders.

Regulations:
Title 8, Chapt. 18, Subchapt. 1 Newborn Biochemical Screening

§ 8:18-1.13. Confidentiality of reports
(a) The reports made pursuant to this subchapter are to be used only by the Department of Health and Senior Services and other agencies that may be designated by the Commissioner and shall not otherwise be divulged or made public so as to disclose the identity of any person and shall be deemed "information relating to medical history, diagnosis, treatment or evaluation" within the meaning of Executive Order No. 26, § 4b1 (McGreevey, August 13, 2002), and, therefore, not "government records" subject to public access or inspection within the meaning of N.J.S.A. 47:1A-1 et seq., particularly N.J.S.A 47:1A-1.1.
(b) Inasmuch as the annual report issued by the Department pursuant to N.J.A.C. 8:18-1.10(a)6iii contains de-identified information and aggregate data, this section shall not apply to the annual report.

**North Dakota**

Regulations:
N.D. Admin. Code

Chapt. 33-06-16 Newborn Screening Program
33-06-16-05. Research and testing materials.
Information and testing materials generated by the newborn screening program under North Dakota Century Code chapter 25-17 are strictly confidential information subject to North Dakota Century Code chapter 23-01.3 and section 23-01-15.
**Oklahoma**

Regulations:
Okla. Admin. Code Title 310

Title 310, Chapt 550, Newborn Screening Program, Subchapt 19
310:550-19-1 Physician Reporting and Medical Records

(c) These reports shall be confidential and may be utilized only for the purpose of ensuring service delivery, program administration, data analysis, and evaluation.

(e) Information that the Department receives under this chapter is confidential and may only be used or disclosed:
   (1) To provide services to the newborn infant and the infant's family;
   (2) To study the relationships of the various factors determining the frequency and distribution of CCHD;
   (3) For State or federally mandated statistical reports; and
   (4) To ensure that the information received by the Department is accurate and reliable.

**Pennsylvania**

Statutes:

Title 35 P.S. Health and Safety, Chapt. 3. Prevention of Spread of Diseases, Infants, Metabolic Diseases
§ 623. Newborn Child Screening and Follow-up Program

(f) Test results for genetic diseases listed in this section and any diseases subsequently added by the department under subsection (d) shall be subject to the confidentiality provisions of the "Disease Prevention and Control Law of 1955."

Regulations:
Pa. Code

Title 28, Chapt. 28. Screening and Follow-up for Disease of the Newborn
§ 28.5. Confidentiality
(a) A health care provider, testing laboratory, the Department or any other entity involved in the newborn screening program may not release any identifying information relating to any newborn child screened in the newborn screening program to anyone other than a parent or guardian of the newborn child or the health care provider for the newborn child designated by a parent or the guardian except as follows:
   (1) As may be necessary to provide services to the newborn child.
   (2) With the consent of the newborn child's parent or guardian.
   (3) With the child's consent when the child is 18 years of age or older, has graduated from high school, has married or has been pregnant.
(b) Only the Department will have the authority to release or authorize the release of nonidentifying information concerning the newborn screening program.
South Carolina

Statutes:
S.C. Code

Title 44, Chapt. 37. Care of the Newly Born
Section 44-37-30. Neonatal testing of children; storage and availability of blood samples for future tests; confidentiality; religious exemption; violation and penalties.

(B) Information obtained as a result of the tests conducted pursuant to this section is confidential and may be released only to a parent or legal guardian of the child, the child's physician, and the child when eighteen years of age or older when requested on a form promulgated in regulation by the department.

Regulations:

Chapt. 61 Department of Health and Environmental Control
61-80 Neonatal Screening for Inborn Metabolic Errors and Hemoglobinopathies

Section E-Assurance of Diagnosis and Follow-up
1. Information obtained as a result of the tests conducted for screening for inborn metabolic errors and hemoglobinopathies is confidential and may be released only to the infant's physician or other staff acting under the direction of the physician, the child's parent or legal guardian, and the child when he/she is eighteen years of age or older.

Tennessee

Statutes:
Tenn. Code

Title 68 Health Chapt. 5, Part 5 Genetic Testing
§ 68-5-506. Creation of birth defects registry -- Advisory committee -- Confidentiality -- Penalty for unauthorized disclosure of confidential information.

(e) (1) All information collected and analyzed pursuant to this section shall be confidential insofar as the identity of the individual patient is concerned and shall be used solely for the purposes provided in this section; provided, that the commissioner may provide access to those scientists approved by the advisory committee who are engaged in demographic, epidemiological or other similar studies related to health, and who agree, in writing as nonstate employees, to be identified and coded while maintaining confidentiality as described in this section and to the centers for disease control (CDC) for inclusion in the National Birth Defects Registry.

Texas

Statutes:

Tex. Health and Safety Code, Title 2, Subtitle B
Chapt. 33. Phenylketonuria, Other Heritable Diseases, Hypothyroidism, and Other Certain Disorders
Sec. 33.0111. Disclosure Statement and Consent
(a) The department shall develop a disclosure statement that clearly discloses to the parent, managing conservator, or guardian of a newborn child subjected to screening tests under Section 33.011:

. . .

(3) that newborn screening spots and associated data are confidential under law and may only be used as described by Section 33.018.

Tex. Health and Safety Code, Title 2, Subtitle B
Chapt. 33. Phenylketonuria, Other Heritable Diseases, Hypothyroidism, and Other Certain Disorders
Sec. 33.018. Confidentiality
(a) In this section:

(a-1) Reports, records, and information obtained or developed by the department under this chapter are confidential and are not subject to disclosure under Chapter 552, Government Code, are not subject to subpoena, and may not otherwise be released or made public except as provided by this section.

Virginia

Statutes:
Code of Virginia

Title 32.1, Chapt. 2, Disease Prevention and Control
§ 32.1-67.1. Confidentiality of records; prohibition of discrimination
. . . No publication of research or statistical data shall be made that identifies any infant having a heritable or genetic disorder.

Title 32.1, Chapt. 2, Disease Prevention and Control
§ 32.1-69. Records confidential; disclosure of results of screening
. . . Except as hereinabove provided, all records maintained as part of any screening program shall be strictly confidential and shall be accessible only to the Board, the Commissioner or his agents or to the local health director who is conducting the screening program except by explicit permission of the person who has been screened if such person is eighteen years of age or over or of such person's parent or guardian if he is under age eighteen.

Title 32.1, Chapt. 2, Disease Prevention and Control
§ 32.1-69.2. Confidentiality of records; publication; authority of Commissioner to contact parents and physicians
The Commissioner and all other persons to whom data is submitted pursuant to § 32.1-69.1 shall keep such information confidential.

Regulations:
Va. Admin. Code Title 12

12VAC5-71-190. Confidentiality of information

The department's newborn screening services and its contractors shall maintain, store, and safeguard client records from unauthorized access as required by law.
Washington

Regulations:
Wash. Admin. Code

Title 246, Chapt. 246-650 Newborn Screening
Section 246-650-001. Purpose.
The purpose of this chapter is to establish board rules to detect, in newborns, congenital disorders leading to developmental impairment or physical disabilities as required by RCW 70.83.050 and to provide protections for the confidentiality of information and human biological specimens submitted pursuant to these requirements.

West Virginia

Regulations:
W. Va. Code of State Rules

Title 64, Series 91, Newborn Screening System
§ 64-91-10. Confidentiality.
10.1. Any person who obtains confidential information while implementing W. Va. Code §16-22-3 and this rule may disclose it only to reporting sources, persons demonstrating a need that is essential to health related research or care of the infant, or as required by law.
10.2. Any person who obtains confidential information while implementing W. Va. Code §16-22-3 and this rule shall provide a written statement of confidentiality stating that he or she fully understands the privacy of the information and will maintain it.

Wisconsin

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(2) Reporting.
(a) Except as provided in par. (b), all of the following shall report in the manner prescribed by the department under sub. (3) (a) 3. a birth defect in an infant or child:

2. A physician who diagnoses the birth defect or provides treatment to the infant or child for the birth defect.

(am) Any hospital in which a birth defect is diagnosed in an infant or child or treatment is provided to the infant or child may report the birth defect in the manner prescribed by the department under sub. (3) (a) 3.

(d) The department may not require a person specified under par. (a) 1. or 2. to report the name of an infant or child for whom a report is made under par. (a) if the parent or guardian of the infant or child refuses to consent in writing to the release of the name or address of the infant or child.

(5) Confidentiality.
(a) Any information contained in a report made to the department under sub. (2) that may specifically identify the subject of the report is confidential.

(4) Confidentiality and Reporting.

No information obtained under this section from the parents or guardian or from tests performed under this section may be disclosed except for use in statistical data compiled by the department without reference to the identity of any individual and except as provided in s. 146.82 (2).

SUPPORTERS

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