## NEW HAMPSHIRE

### Birth Defects Surveillance System

<table>
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<tr>
<th>State</th>
<th>Statute/Rule</th>
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<tr>
<td>NH</td>
<td>STATUTE: Title X</td>
<td>141-J: Birth Conditions Program Authorized. The department of health and human services may establish and maintain a statewide, population-based public health surveillance program on birth conditions, to be known as the New Hampshire birth conditions program if established…</td>
<td>141-J:3 Program Access to Health Information. I. Health care providers, health care facilities, clinics, laboratories, medical records departments, and state offices, agencies, and departments shall allow the program to have access to individually identifiable health information relating to the occurrence of birth conditions in children, infants, or stillborn fetuses. The program may acquire the same information relating to New Hampshire residents from health care facilities, birth conditions surveillance programs, and other sources in other states. The program shall not provide individually identifiable health information relating to New Hampshire residents to any similar program operated by any other state or the federal government.</td>
<td>141-J:1…The program shall: I. Determine the prevalence and trends of birth conditions among New Hampshire residents. II. Develop and assess strategies for the prevention of birth conditions.</td>
<td>NO</td>
<td>NO – only identifiable data not collected</td>
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<td>Chapter 141-J</td>
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<td>NEW RULE PROPOSED:</td>
<td>141-J:5 Election Not to Participate in the Program. I. An individual who is the subject of individually identifiable health information may elect not to participate in the program. If the individual is a minor or is legally incompetent, the individual’s parent or legal guardian may so elect on the individual’s behalf. II. The program shall notify each individual with a confirmed birth condition diagnosis whose individually identifiable health information it proposes to include in the program of the election prior to obtaining any individually identifiable health information relating to the individual, other than name and address and diagnosis. The program shall not obtain any individually identifiable health information for any individual who does not have a confirmed birth condition diagnosis and shall retain the name and address only of any such individual for a period not to exceed 2 years. … V. If the program has notified an individual pursuant to paragraph II or III, and within 60 days of providing such notice has not received the individual’s election not to participate in the program, the program may obtain access to, or retain, as the case may be, individually identifiable health information relating to the individual. VI. The program shall not acquire, retain, use, or disclose individually identifiable health information, including birth condition, with respect to those individuals who have elected not to participate in the program under paragraph I or RSA 141-J:5, I. The program shall retain a list of those individuals who have elected not to participate in the program and the dates of such elections but shall not disclose this information to any other entity.</td>
<td>141-J:6 Rights of Individuals. An individual with respect to whom the program retains individually identifiable health information may: I. Elect at any time not to participate in the program. Upon such election, the program shall remove any individually identifiable health information relating to the individual. II. Review any individually identifiable health information in program records relating to the individual.</td>
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<td>Chapter He-P 3000</td>
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<td>Part He-P3012</td>
<td>(Public hearing 1/20/09)</td>
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### III. Program Access to Health Information

(a) In accordance with RSA 141-J:3 and this section, health care providers and facilities shall allow the NHBCP to have access to health information and individually identifiable health information relating to the occurrence of birth conditions in children, infants, and stillborn fetuses.

(b) At least annually, the NHBCP shall direct health care providers and facilities to generate a list of presumed cases of birth conditions. This list shall include only the information allowed by (d)(1) below.

(c) The NHBCP medical records abstractor shall conduct on-site reviews of medical records to determine which cases identified in (b) above are confirmed cases as outlined in the “Guidelines for Conducting Birth Defects Surveillance” (June 2004) established by the National Birth Defects Prevention Network.

(d) For confirmed cases determined in accordance with (c) above, the medical records abstractor:

1. Shall collect the diagnosis, the health care provider’s name and address, and only the following individually identifiable information about the child, infant, or stillborn fetus:
   - Name; and
   - Address, including town or city, state and postal code at the time of birth; and
2. May collect additional non-individually identifiable health information about the child, infant, or stillborn fetus in accordance with the “Guidelines for Conducting Birth Defect Surveillance” (June 2004) established by the National Birth Defects Prevention Network.

(e) If the NHBCP has not received a completed opt out form from the individual in accordance with He-P 3012.04, the medical records abstractor shall return to the health care provider or facility to conduct a second on-site visit and perform on-site medical record abstraction to collect only that information described in (f) through (i) below. This visit shall be conducted no earlier than 60 days after the opt out packet was mailed.

(f) For those cases allowed under (e) above, the following additional individually identifiable health information shall be collected for the child, infant, or stillborn fetus:

1. Date of birth and death, if applicable;
2. Results of any genetic testing related to the birth condition; and
3. Medical record number.

### II. Program Records Not Public Records

Any individually identifiable health information acquired, used, disclosed, or retained by the program shall not constitute a public record. The names and addresses of individuals who have elected not to participate in the program shall not be a public record. No individually identifiable health information retained by the program shall be discoverable or compelled to be produced pursuant to subpoena or compelled testimony in any legal proceeding without the written authorization of the person about whom the information relates. Analyses and compilations of data that do not disclose individually identifiable health information shall be available to the public under RSA 91-A.

### III. Promote Scientific Collaboration

Promote scientific collaboration through data analysis, investigations, and epidemiological studies on the public health impact of birth conditions and possible cause of birth conditions, including exposure to environmental or occupational hazards, maternal and stillborn fetal conditions, and illnesses or complications during pregnancy, labor, or delivery.
(g) For those cases allowed under (e) above, the following individually identifiable information shall be collected for the mother: (1) First, middle and last name; (2) Date of birth;
(h) For those cases allowed under (e) above, the following individually identifiable health information shall be collected for the father: (1) First, middle and last name; and (2) Date of birth.

(j) The NHBCP shall acquire health information and individually identifiable health information relating to New Hampshire residents with birth conditions only from those health care facilities, birth conditions surveillance programs, or other sources in other states with which the department has entered into an interstate memorandum of agreement for those purposes.

(k) The NHBCP shall not obtain any individually identifiable health information for any individual who does not have a confirmed birth condition diagnosis and shall only retain the name and address of any such individual for a period not to exceed 2 years.

**He-P3012.04 Election Not to Participate in the NHBCP.**
(a) If an individual, or the parent or guardian of a minor or an individual who is legally incompetent, objects to the collection of individually identifiable health information by the NHBCP, the individual or a parent or guardian of a minor, may elect not to participate in the program, in accordance with RSA 141-J:5 and RSA 141-J:6,1.
(b) Within 7 business days of collecting data from a confirmed case per He-P 3012.03(d), the NHBCP shall send an opt out information packet which shall include:
   (1) A letter to the individual, or the parent or guardian of a minor or an individual who is legally incompetent, explaining the collection of the birth condition data by the NHBCP under RSA 141-J;
   (2) A NHBCP fact sheet about the nature and purpose of the program including the telephone number, fax number, mailing address, and email address of the NHBCP;
   (3) Information about state-supported early intervention and prevention services; and
   (4) An opt out form with:
      a. A statement that the failure to complete and return the opt out form within 60 calendar days of the date of the letter means that their individually identifiable health information as listed in He-P 3012.03 shall be collected by the NHBCP;
      b. A statement that the individual, or the parent or guardian of a minor or an individual who is legally incompetent, may elect not the participate at any time in the future in accordance with RSA 141-J:6,1 and He-P 3012.06(a); and
      c. Information on what will occur as a result of opting out of the program.
(c) If information packets described in (b) above are returned to the NHBCP as undeliverable, the program shall contact the individual’s health care provider for the individual’s most current address. The provider shall disclose that information solely for the purpose of the NHBCP contacting the individual regarding the opt out procedures.

**141-J:8 Privacy and Confidentiality Protections. I.**
Any person allowed access to individually identifiable health information in program records shall sign a confidentiality agreement, in a form specified by the department, requiring adherence to privacy and security protections equivalent to or greater than the protections provided in this chapter.

[AMENDS GENETIC PRIVACY LAW TO ALLOW REPORTING TO BIRTH DEFECTS SURVEILLANCE]:

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Updated August 2012. All state statutes and department rules originally accessed online July/Aug 2008. Statute/Rule data not inclusive. For comprehensive or updated language, access complete statute and rules online, at local library or through the state legislature. www.cchfreedom.org
(d) The NHBCP shall send letters to acknowledge the individual’s decision to opt out of the NHBCP within 7 business days of receipt of the completed opt out form.

(e) The NHBCP shall develop a list of individuals who have confirmed birth conditions but who have elected to opt out of the program, and the dates of such elections, to be used only as a means to verify that an individual or the parent or guardian of a minor has elected to opt out. This list shall not be disclosed to any entity or individual outside of the NHBCP.

186:2 Conditions of Genetic Testing. Amend RSA 141-H:2, III to read as follows:

III. Except as provided in paragraph II, or authorized by RSA 141-J, no person shall disclose to any other person that an individual has undergone genetic testing, and no person shall disclose the results of such testing to any other person, without the prior written and informed consent of the individual, the parent, guardian, or custodian if the individual is a minor under the age of 18, or the legal guardian or conservator if the individual is an incompetent person. Discussion and disclosure of genetic testing for a patient, requested of a physician by a patient, by appropriate professionals within a physician’s medical practice or hospital shall not be a violation of this chapter.
## Cancer Surveillance System

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<tr>
<td>NH</td>
<td>STATUTE: Title X, Chapter 141-B</td>
<td>141-B:5 Cancer Registry Established. – There shall be established in the department a cancer registry for compilation and analysis of information relating to the incidence, diagnosis, and treatment of cancer.</td>
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<td>141-B:9 Disclosure; Confidentiality.</td>
<td>NO</td>
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<td>RULE: PART He-P 304</td>
<td>141-B:8 Rulemaking. – The commissioner shall adopt rules, pursuant to RSA 541-A, relative to: I. Conducting prevention and screening services and delivering education programs; II. Content and design of all forms and reports required by this chapter; III. The procedures for disclosure of information gathered by the cancer registry, by monitoring and evaluating health data, and from completed risk assessments; and IV. Any other matter necessary to the administration of this chapter.</td>
<td></td>
<td>141-B:7 Reporting. – All facilities shall provide a report to the cancer registry, including social security numbers if persons were given the option at the original point of collection to provide social security numbers voluntarily, containing information regarding a cancer diagnosed or being treated.</td>
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<td>141-B:10 Maintenance of Reports. – Reports provided to the cancer registry under RSA 141-B:7, and analyses and data prepared under RSA 141-B:4, II, III, and V shall be maintained by the department in a manner suitable for chronic disease and cancer research purposes, and shall be available to persons as prescribed in RSA 141-B:9.</td>
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<td>141-B:9 Disclosure; Confidentiality.</td>
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<td>He-P 304.08 Procedures for Disclosure of Protected Health Information.</td>
<td>(a) The SCR shall use and disclose protected health information in accordance with RSA 141-B:9 and the provisions of 45 CFR 164 generally, and specifically, 45 CFR 164.502, 164.506 and 164.512. … (c) A report submitted to the SCR concerning an individual, and any other information maintained by the SCR, which, because of a personal identifier, can be readily associated with an individual, shall only be released:…(5) To persons conducting health related research, upon receipt and approval pursuant to He-P 304.09 of a written application to the department, which shall be signed by the applicant and includes:…</td>
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## Newborn Genetic Testing & Surveillance System

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| NH    | STATUTE: Title X, Chapter 132:10-a to c RULE: Chapter He-P 3000 | 132:10-a Newborn Screening Tests Required; Newborn Screening Advisory Committee. –  
I. The physician, hospital, nurse midwife, midwife, or other health care provider attending a newborn child shall test a newborn child for metabolic disorders. Such tests shall include, but not be limited to, phenylketonuria, galactosemia, homocystinuria, maple syrup urine disease, and hypothyroidism. Additional disorders shall be added to the newborn screening panel based upon, but not limited to, the following considerations:  
(a) The disorder is well-defined with a known incidence.  
(b) The disorder is associated with significant morbidity and/or mortality.  
(c) The disorder can be detected with a screening test that is ethical, safe, accurate, and cost-effective.  
(d) Effective treatment exists for the disorder, and that early treatment, meaning before the onset of symptoms, is more effective in improving health outcomes than later treatment…  
III. The department of health and human services shall establish a newborn screening advisory committee which shall include a member of the oversight committee on health and human services, established in RSA 126-A:13, and representation from health care subspecialties, as determined by the department. | 132:10-c Exception. – The provisions of RSA 132:10-a and 10-b shall not apply if the parents of such child object thereto.  
He-P 3008.03 Definitions.  
…(e) “Dried blood spot (DBS)” means a specimen of blood obtained from an infant through the heel stick procedure, which is then applied to a filter paper and dried…  
(j) “Informed dissent” means the written refusal by an infant’s parent or guardian to participate in newborn screening as defined in this rule.  
(k) “Laboratory” means the testing facility authorized by the state of New Hampshire to conduct DBS testing on its behalf.….  
(n) “Newborn screening program (NSP)” means the department program, which has responsibility for managing all aspects of infant screening pursuant to RSA 132:10-a. | 132:10-a. III-a. The department shall ensure that the laboratory analyzing tests authorized under paragraph I destroys any samples no later than 6 months following the completion of testing. Any samples taken for newborn screening shall only be used for tests require under this section. No such samples may be used for other research or DNA testing purposes unless authorized by the parent or guardian. | NO | YES |
<table>
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<th>He-P 3008.18 Quality Assurance</th>
<th>He-P 3008.10 Disposal of DBS Residual</th>
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<td>(e) The NSP [Newborn Screening Program] shall compare the data sets of infants screened with New Hampshire birth certificate files.</td>
<td>(a) The testing laboratory shall store DBS specimens in sealed bags of low gas permeability containing a desiccant and humidity indicator at –20 degrees Celsius.</td>
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<td>(f)</td>
<td>(b) The testing laboratory shall destroy DBS specimens six months after the collection date, in a manner consistent with applicable federal requirements relating to the disposal of human blood and body fluids per OSHA regulations 29 CFR 1910.1030.</td>
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<td>(c) If the storage environment of any DBS is found to have deviated from the required conditions described in (a) above, such that the stability of the specimen is likely to have been affected, the testing laboratory shall first notify the NSP and shall then destroy the DBS specimen.</td>
<td>(c) If the newborn screening tests are performed by a laboratory other than that used by the NSP, the infant’s healthcare provider shall request all tests required by the NSP and provide a copy of these test results to the NSP.</td>
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<td>He-P 3008.11 Requests for DBS or Related Records. Residual DBS specimens and related records may be retrieved for other purposes only with the written authorization of a parent or guardian.</td>
<td>He-P 3008.18 Quality Assurance. (c) The NSP shall provide upon request:</td>
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<td>(4) A copy of the statement of dissent shall be provided to the parent or guardian.</td>
<td>(1) Information regarding acceptable procedures for the collection, handling, short-term storage and transport of a DBS;</td>
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<td>(d) Newborn screening tests shall be conducted as follows:</td>
<td>(2) Information regarding newborn screening that shall be given to and reviewed with the parent or guardian of each infant prior to testing; and</td>
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<td>(1) The DBS shall be collected from the infant through the heel stick procedure and applied to the filter paper obtained from the NSP, and</td>
<td>(3) Text to be used in statements of dissent…</td>
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## Vaccination Surveillance System

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<tr>
<td>NH</td>
<td>STATUTE: Title X, Chapter 141-C</td>
<td>141-C:20-f Immunization Registry. – I. The department shall establish and maintain a state immunization registry. The registry shall be a single repository of accurate, complete and current immunization records to aid, coordinate, and promote effective and cost-efficient disease prevention and control efforts…</td>
<td>141-C:20-f …II. No patient, or the patient's parent or guardian if the patient is a minor, shall be required to participate in the immunization registry. III. Physicians, nurses, and other health care providers may report an immunization to the immunization registry unless the patient, or the patient's parent or guardian if the patient is a minor, refuses to allow reporting of this information… X. No health care provider shall discriminate in any way against a person solely because that person elects not to participate in the immunization registry.</td>
<td>NO</td>
<td>YES</td>
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<td>RULE: PART He-P 307</td>
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V. The information contained in the registry shall be used for the following purposes:

(a) To ensure that registrants receive all recommended immunizations in a timely manner by providing access to the registrant's immunization record.
(b) To improve immunization rates by facilitating notice to registrants of overdue or upcoming immunizations.
(c) To control communicable diseases by assisting in the identification of individuals who require immediate immunization in the event of a disease outbreak.

VI. The commissioner shall adopt rules under RSA 541-A concerning the following:

(a) The establishment and maintenance of the immunization registry.
(b) The methods for submitting and content of reports of immunizations.
(c) Procedures for the patient, or the patient's parent or guardian if the patient is a minor, to decline to participate in the registry.

VII. Any person reporting, receiving, or disclosing information to or from the immunization registry as authorized by this section or by any rule adopted pursuant to this section shall not be liable for civil damages of any kind connected with such submission or disclosure of immunization information.
|   | Procedures for the registrant, or the registrant's parent or guardian if the registrant is a minor, to review and correct information contained in the registry.  
|---|---
| (e) | Procedures for the registrant, or the registrant's parent or guardian if the registrant is a minor, to withdraw consent for participation at any time and to remove information from the registry.  
| (f) | Limits on and methods of access to the registry by those authorized to gain access under paragraph IV of this section.  
| (g) | Procedures for managed care organizations to obtain summary statistics of immunization information on managed care organization members from the immunization registry. |
| (1) | An individual shall:  
| a. | Make a request to their primary immunization provider; or  
| b. | Submit to the commissioner a notarized letter containing the following information:  
| 1. | His/her name;  
| 2. | His/her address;  
| 3. | His/her date of birth; and  
| 4. | A statement indicating the nature of his/her request. |
| (2) | If the registrant is a minor, a parent of the registrant shall:  
| a. | Make a request to the minor’s primary immunization provider; or  
| b. | Submit to the commissioner a notarized letter containing the following information:  
| 1. | The registrant’s name;  
| 2. | The registrant’s address;  
| 3. | A copy of the birth certificate of the registrant; and  
| 4. | A statement indicating the nature of his/her request. |
| (3) | If the registrant is a minor who has a court-appointed guardian, the court-appointed guardian shall:  
| a. | Make a request to the minor’s primary immunization provider; or  
| b. | Submit to the commissioner a notarized letter containing the following information:  
| 1. | The registrant’s name;  
| 2. | The registrant’s address;  
| 3. | A copy of the birth certificate of the registrant;  
| 4. | A certified copy of the order or decree which appoints the guardian; and  
| 5. | A statement indicating the nature of his/her request. |