ASSEMBLY BILL NO. 238–ASSEMBLYMEN EVANS, MANENDO, GIBBONS, HUMKE, WILLIAMS, GOLDWATER, SEGERBLOM, CHOWNING, GIUNCHIGLIANI, ARBERRY, HETTRICK, FREEMAN AND CEGAVSKE

## FEBRUARY 15, 1999

## Referred to Concurrent Committees on Health and Human Services and Ways and Means

SUMMARY—Provides for establishment and maintenance of system for collection and analysis of information concerning birth defects and other poor reproductive outcomes. (BDR 40-72)

FISCAL NOTE: Effect on Local Government: No. Effect on the State or on Industrial Insurance: Yes.

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EXPLANATION - Matter in bolded italics is new; matter between brackets [omitted material] is material to be omitted.

AN ACT relating to public health; requiring the establishment and maintenance of a system for the collection and analysis of information concerning birth defects and other poor reproductive outcomes; restricting access to and the use of information obtained by the system; and providing other matters properly relating thereto.

## THE PEOPLE OF THE STATE OF NEVADA, REPRESENTED IN SENATE AND ASSEMBLY, DO ENACT AS FOLLOWS:

- **Section 1.** NRS 440.170 is hereby amended to read as follows:
- 440.170 1. All certificates in the custody of the state registrar are
- 3 open to inspection subject to the provisions of this chapter. It [shall be] is
  - unlawful for any employee of the state to disclose data contained in vital
- 5 statistics, except as authorized by this chapter or by the board.
- 2. Information in vital statistics indicating that a birth occurred out of wedlock [shall] *must* not be disclosed except upon order of a court of
- 8 competent jurisdiction.

- 3. The board [may permit]:
- 10 (a) Shall allow the use of data contained in vital statistics to carry out 11 the provisions of sections 3 to 10, inclusive, of this act; and
- (b) May allow the use of data contained in vital statistics [records] for
- other research purposes, but without identifying the persons to whom the
- 14 records relate.

- **Sec. 2.** Chapter 442 of NRS is hereby amended by adding thereto the provisions set forth as sections 3 to 10, inclusive, of this act.
- Sec. 3. As used in sections 3 to 10, inclusive, of this act, unless the context otherwise requires, the words and terms defined in sections 4, 5 and 6 of this act have the meanings ascribed to them in those sections.
- Sec. 4. "Birth defect" means any structural or chemical abnormality present in a child at birth.
  - Sec. 5. "Poor reproductive outcome" includes stillbirths.
- 9 **Sec. 6.** "System" means the system established and maintained pursuant to section 7 of this act.
- Sec. 7. 1. The health division, in cooperation with the University of
  Nevada School of Medicine, shall establish and maintain a statewide
  system for the collection and analysis of information concerning birth
  defects and other poor reproductive outcomes.
- 15 2. The state board of health may adopt such regulations as it deems appropriate to carry out the provisions of sections 3 to 10, inclusive, of this act.
- Sec. 8. 1. The chief administrative officer of each facility that provides health care services in this state or his representative shall make available to the state health officer or his representative the records of the facility regarding:
- 22 (a) Patients who are under 7 years of age and have been diagnosed 23 with one or more birth defects; and
  - (b) Patients discharged with poor reproductive outcomes.
- 25 2. The chief administrative officer of each hospital that provides any of the categories of service set forth in NRS 449.021 or his representative shall maintain and make available to the state health officer or his representative a list of:
- (a) Patients who are under 7 years of age and have been diagnosed
   with one or more birth defects set forth in diagnostic code categories 740
   to 759.9, inclusive, of the "International Classification of Diseases, 9th
   Edition, Clinical Modification," published by the Department of Health
   & Human Services; and
  - (b) Patients discharged with a diagnosis of stillbirth.

- The name of a patient must be maintained on the list for at least 5 years after the patient is discharged from the hospital.
- 37 3. The state health officer or his representative shall abstract from the records and lists required to be maintained by this section such information as is required by the state board of health for inclusion in the system.
- Sec. 9. 1. Information obtained by the system from any source may be used only:

- (a) To investigate the causes of birth defects and other poor reproductive outcomes;
- (b) To determine, evaluate and develop strategies to prevent the occurrence of birth defects and other poor reproductive outcomes;
- (c) To assist in the early detection of birth defects;
- (d) To assist in ensuring the delivery of services for children identified with birth defects; and
- (e) For such other purposes as may be approved by the state health officer or his representative.
  - 2. The state board of health shall adopt regulations to ensure that:
- (a) Access to information contained in the system is limited to persons approved by the state health officer or his representative who are:
  - (1) Employed by the health division;

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- (2) Employed by the University of Nevada School of Medicine; or
- (3) Engaged in demographic, epidemiological or other similar research related to health, and who agree in writing to comply with the provisions of this section and the regulations of the state board of health.
- (b) Any information obtained by the system that would reveal the identity of a patient remains confidential and is used solely for the purposes set forth in this section.
- 3. This section does not prohibit the publishing of statistical compilations relating to birth defects and other poor reproductive outcomes that do not in any manner identify individual patients or individual sources of information.
  - Sec. 10. The health division shall maintain an accurate record of each person who is not employed by the health division or the University of Nevada School of Medicine and is given access to information in the system. The record must include:
    - 1. The name and title of the person authorizing access;
- 2. The name, title and organizational affiliation of each person given access:
  - 3. The dates of access;
  - 4. The specific purpose for which the information is to be used; and
- 5. The results of the independent research.
- Sec. 11. NRS 442.115 is hereby amended to read as follows:
- 442.115 1. The state board of health, upon the recommendation of the state health officer, shall adopt regulations governing examinations and tests required for the discovery in infants of preventable inheritable disorders, including tests for the presence of sickle cell anemia.
- 2. Any physician, midwife, nurse, maternity home or hospital of any nature [attendant on] attending or assisting in any way [whatever] any infant, or the mother of any infant, at childbirth shall make or cause to be
- 43 made an examination of the infant, including standard tests, to the extent

- required by regulations of the state board of health as *is* necessary for the discovery of conditions indicating such disorders.
- 3. If the examination and tests reveal the existence of such conditions in an infant, the physician, midwife, nurse, maternity home or hospital [attendant on] attending or assisting at the birth of the infant shall immediately:
- (a) Report the condition to *the state health officer or his representative*, the local health officer of the county or city within which the infant or the mother of the infant resides, and the local health officer of the county or city in which the child is born; and
- (b) Discuss the condition with the parent, parents or other persons responsible for the care of the infant and inform them of the treatment necessary for the amelioration of the condition.
- 4. An infant is exempt from examination and testing if either parent files a written objection with the person or institution responsible for making the examination or tests.
  - **Sec. 12.** NRS 449.720 is hereby amended to read as follows:
- 18 449.720 Every patient of a medical facility or facility for the dependent has the right to:
  - 1. Receive considerate and respectful care.

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- 2. Refuse treatment to the extent permitted by law and to be informed of the consequences of that refusal.
- 23 3. Refuse to participate in any medical experiments conducted at the facility.
  - 4. Retain his privacy concerning his program of medical care.
- 26 Discussions of a patient's care, consultation with other persons concerning
- 27 the patient, examinations or treatments, and all communications and
- records concerning the patient, except as otherwise provided in NRS
- 29 108.640 and 449.705, *sections 3 to 10, inclusive, of this act* and chapter
- 30 629 of NRS, are confidential. The patient must consent to the presence of
- any person who is not directly involved with his care during any
- 32 examination, consultation or treatment.
- 5. Have any reasonable request for services reasonably satisfied by the facility considering its ability to do so.
- 6. Receive continuous care from the facility. The patient must be informed:
  - (a) Of his appointments for treatment and the names of the persons available at the facility for those treatments; and
- 39 (b) By his physician or an authorized representative of the physician, of his need for continuing care.
- Sec. 13. NRS 458.055 is hereby amended to read as follows:
- 42 458.055 1. To preserve the confidentiality of any information
- 43 concerning persons applying for or receiving any services pursuant to NRS

- 458.010 to 458.360, inclusive, the bureau may establish and enforce rules governing the confidential nature, custody, use and preservation of the records, files and communications filed with the bureau.
- 2. Wherever information concerning persons applying for and receiving any services pursuant to NRS 458.010 to 458.360, inclusive, is furnished to or held by any other government agency or a public or private institution, the use of such information by the agency or institution is subject to the rules established by the bureau pursuant to subsection 1.
- 3. Except as otherwise provided in NRS 449.705, *sections 3 to 10*, *inclusive*, *of this act* and chapter 629 of NRS and except for purposes directly connected with the administration of NRS 458.010 to 458.360, inclusive, a person shall not disclose, use or permit to be disclosed, any confidential information concerning a person receiving services pursuant to NRS 458.010 to 458.360, inclusive.

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- Sec. 14. NRS 458.280 is hereby amended to read as follows:
  458.280 1. Except as otherwise provided in subsection 2, NRS
  449.705, sections 3 to 10, inclusive, of this act and chapter 629 of NRS,
  the registration and other records of a treatment facility are confidential
  and must not be disclosed to any person not connected with the treatment
  facility without the consent of the patient.
  - 2. The provisions of subsection 1 do not restrict the use of a patient's records for the purpose of research into the causes and treatment of alcoholism if such information is not published in a way that discloses the patient's name or other identifying information.
  - **Sec. 15.** NRS 629.171 is hereby amended to read as follows:
  - 629.171 It is unlawful to disclose or to compel a person to disclose the identity of a person who was the subject of a genetic test or to disclose genetic information of that person in a manner that allows identification of the person, without first obtaining the informed consent of that person or his legal guardian pursuant to NRS 629.181, unless the information is disclosed:
- 1. To conduct a criminal investigation, an investigation concerning the death of a person or a criminal or juvenile proceeding;
- 2. To determine the parentage or identity of a person pursuant to NRS 56.020;
- 36 3. To determine the paternity of a person pursuant to NRS 126.121 or 425.384;
- 4. Pursuant to an order of a court of competent jurisdiction;
- 5. By a physician and is the genetic information of a deceased person that will assist in the medical diagnosis of persons related to the deceased person by blood;
- 6. To a federal, state, county or city law enforcement agency to establish the identity of a person or dead human body;

- To determine the presence of certain inheritable preventable disorders in an infant pursuant to NRS 442.115 or a provision of federal law; 3
- To carry out the provisions of sections 3 to 10, inclusive, of this 8. 4 act; or
- [8.] 9. By an agency of criminal justice pursuant to NRS 179A.075.
- **Sec. 16.** NRS 652.190 is hereby amended to read as follows:
- 652.190 1. A laboratory may examine specimens only at the request of: 9
- (a) A licensed physician; 10

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- (b) Any other person authorized by law to use the findings of laboratory 11 12 tests and examinations; or
  - (c) If the examination can be made with a testing device or kit which is approved by the Food and Drug Administration for use in the home and which is available to the public without a prescription, any person.
  - Except as otherwise provided in NRS 441A.150 and 652.193 and section 8 of this act, the laboratory may report the results of the examination only to the person requesting the test or procedure and to the patient for whom the testing or procedure was performed. The laboratory report must contain the name of the laboratory.
  - If a specimen is accepted by a laboratory and is referred to another laboratory, the name and address of the other laboratory must be clearly shown by the referring laboratory on the report to the person requesting the test or procedure.
- Whenever an examination is made pursuant to paragraph (c) of subsection 1, the laboratory report must contain a provision which 26 recommends that the results of the examination be reviewed and interpreted by a physician or other licensed provider of health care. 28
  - **Sec. 17.** NRS 652.193 is hereby amended to read as follows:
- 30 652.193 1. A Except as otherwise provided in section 8 of this act,
- *a* licensed laboratory may release the results of tests performed at the 31
- laboratory regarding a patient of a rural hospital only to: 32
- (a) The patient; 33
- 34 (b) The physician who ordered the tests; and
- (c) A provider of health care who is currently treating or providing 35 assistance in the treatment of the patient. 36
  - As used in this section:
- 38 (a) "Provider of health care" has the meaning ascribed to it in NRS 629.031. 39
- (b) "Rural hospital" has the meaning ascribed to it in NRS 449.0177. 40