LEGISLATURE OF NEBRASKA

ONE HUNDREDTH LEGISLATURE

SECOND SESSION

LEGISLATIVE BILL 1003

Introduced by Pahls, 31.

Read first time January 16, 2008

Committee: Health and Human Services

A BILL

adopt the Saving the Cure Act; to provide for an accredited laboratory at the University of Nebraska Medical Center to conduct research as prescribed; to	1	FOR AN	ACT relating to public health and welfare; to amend
accredited laboratory at the University of Nebraska Medical Center to conduct research as prescribed; to provide for funding; to harmonize provisions; and to	2		section 71-7611, Revised Statutes Supplement, 2007; to
Medical Center to conduct research as prescribed; to provide for funding; to harmonize provisions; and to	3		adopt the Saving the Cure Act; to provide for an
6 provide for funding; to harmonize provisions; and to	4		accredited laboratory at the University of Nebraska
	5		Medical Center to conduct research as prescribed; to
7 repeal the original section.	6		provide for funding; to harmonize provisions; and to
	7		repeal the original section.

⁸ Be it enacted by the people of the State of Nebraska,

1 Section 1. Sections 1 to 7 of this act shall be known and

- 2 may be cited as the Saving the Cure Act.
- 3 Sec. 2. It is the public policy of this state to
- 4 encourage the donation, collection, and storage of stem cells
- 5 collected from postnatal tissue and fluid and to make such stem
- 6 cells available for medical research and treatment, to promote
- 7 principled and ethical stem cell research, and to encourage stem
- 8 cell research with immediate clinical and medical applications.
- 9 Sec. 3. For purposes of the Saving the Cure Act:
- 10 (1) Amniotic fluid means the fluid inside the amnion;
- 11 (2) Commission means the Commission for Saving the Cure
- 12 <u>established in section 5 of this act;</u>
- 13 (3) Placenta means the organ that forms on the inner wall
- 14 of the human uterus during pregnancy;
- 15 (4) Postnatal tissue and fluid means the placenta,
- 16 <u>umbilical cord</u>, and amniotic fluid expelled or extracted in
- 17 connection with the birth of a human being;
- 18 (5) Stem cells means unspecialized or undifferentiated
- 19 cells that can self-renew and have the potential to differentiate
- 20 into specialized cell types; and
- 21 (6) Umbilical cord means the gelatinous tissue and blood
- 22 vessels connecting an unborn human being to the placenta.
- 23 Sec. 4. (1) Not later than June 30, 2009, the commission
- 24 shall establish a network in partnership with public or private
- 25 hospitals in Nebraska for the purpose of facilitating the

1 collection and transportation of postnatal tissue and fluid to

- 2 (a) a hospital for purposes of medical treatment or research,
- 3 (b) to a private postnatal tissue and fluid bank, or (c) to a
- 4 public postnatal tissue and fluid bank established in another state
- 5 when needed. The network shall be known as the Nebraska Newborn
- 6 Umbilical Cord Blood Network and shall facilitate making such
- 7 tissue and fluid available for medical research and treatment in
- 8 accordance with the Saving the Cure Act.
- 9 (2) The commission shall develop a program to educate
- 10 pregnant women with respect to the banking of postnatal tissue and
- 11 fluid. The program shall include:
- 12 (a) Notice of the existence of the Nebraska Newborn
- 13 Umbilical Cord Blood Network;
- 14 (b) An explanation of the difference between public and
- 15 private postnatal tissue and fluid banking programs;
- 16 (c) The medical process involved in the collection and
- 17 storage of postnatal tissue and fluid;
- 18 (d) The current and potential future medical uses of
- 19 stored postnatal tissue and fluid;
- 20 (e) The benefits and risks involved in the banking of
- 21 postnatal tissue and fluid; and
- 22 (f) The availability and cost of storing postnatal tissue
- 23 and fluid in public and private umbilical cord blood banks.
- 24 (3) Beginning June 30, 2009, all physicians and hospitals
- 25 in Nebraska may inform pregnant patients of the full range of

1 options for donation of postnatal tissue and fluids no later than

- 2 thirty days after the commencement of the patient's third trimester
- 3 of pregnancy or at the first consultation between the attending
- 4 physician or the hospital, whichever is later.
- 5 (4) This section does not prohibit a person from donating
- 6 postnatal tissue or fluid to a private blood and tissue bank or
- 7 storing postnatal tissue or fluid with a private blood and tissue
- 8 bank.
- 9 (5) Prior to facilitating the collection or
- 10 transportation of any postnatal tissue or fluid (a) for
- 11 medical research or (b) to a postnatal tissue and fluid bank
- 12 established in another state, the commission shall establish
- 13 that the hospital or bank has or is subject to an institutional
- 14 review board which is available on an ongoing basis to review the
- 15 research procedures and conduct of any person desiring to conduct
- 16 research with postnatal tissue and fluid. The institutional review
- 17 board shall have established procedures to protect and ensure the
- 18 privacy rights of postnatal tissue and fluid donors consistent with
- 19 applicable federal guidelines.
- 20 Sec. 5. (1) The Commission for Saving the Cure is
- 21 created. The commission shall consist of fifteen members appointed
- 22 by the Governor. Eight members shall be appointed for initial terms
- 23 of three years, and seven members shall be appointed for initial
- 24 terms of two years. Successors to such initial appointees shall
- 25 serve terms of three years. The Governor shall designate one of the

1 persons appointed to be the chairperson of the commission. Members

- 2 of the commission shall be eligible to succeed themselves.
- 3 (2) At least one member may be a physician licensed to
- 4 practice medicine in this state, at least one member may be a
- 5 recognized medical ethicist with a degree in medicine, medical
- 6 ethics, or a related field, at least one member may be a medical
- 7 researcher in stem cell research, and at least one member may be an
- 8 attorney with experience in health policy law.
- 9 (3) The initial terms of office shall begin on January 1,
- 10 2009. Appointments shall be made no later than December 1, 2008.
- 11 Thereafter, appointments of successors shall be made no later than
- 12 December 1 of the year prior to which the member's term of office
- 13 expires. Vacancies shall be filled for the unexpired term. Members
- 14 of the commission shall be reimbursed for the actual and necessary
- 15 expenses incurred in carrying out their duties as such members as
- 16 provided in sections 81-1174 to 81-1177.
- 17 <u>(4) The commission shall meet at least four times per</u>
- 18 year at the call of the chairperson or upon the request of at least
- 19 seven of its members.
- 20 (5) The commission shall be within the Department of
- 21 <u>Health and Human Services for administrative purposes only.</u>
- 22 Sec. 6. (1) The commission shall have the following
- 23 duties and responsibilities:
- 24 (a) To investigate the implementation of the Saving the
- 25 Cure Act and to recommend to the Legislature any changes in the act

- the commission deems necessary;
- 2 (b) To make available to the public the records of all
- 3 meetings of the commission and of all business transacted by the
- 4 commission;
- 5 (c) To oversee the operation of the Nebraska Newborn
- 6 Umbilical Cord Blood Network established under section 4 of this
- 7 act;
- 8 (d) To promote awareness of the Nebraska Newborn
- 9 Umbilical Cord Blood Network and encourage donation of postnatal
- 10 tissue and fluid to the network;
- 11 (e) To ensure the privacy of persons who donate postnatal
- 12 tissue and fluid to the Nebraska Newborn Umbilical Cord Blood
- 13 Network consistent with applicable federal guidelines;
- 14 (f) To develop a plan for making postnatal tissue and
- 15 fluid collected under the Saving the Cure Act available for medical
- 16 research and treatment and to ensure compliance with all relevant
- 17 national practice and quality standards relating to such use;
- 18 (g) To develop a plan for private storage of postnatal
- 19 tissue and fluid for medical treatment or to make potential donors
- 20 aware of private storage options for postnatal tissue and fluid;
- 21 (h) To participate in the National Cord Blood Program and
- 22 to register postnatal tissue and fluid collected with registries
- 23 operating in connection with such program;
- 24 <u>(i) To make grants and enter into agreements to</u>
- 25 support stem cell research with immediate and clinical medical

- 1 applications;
- 2 (j) To employ such staff and to enter into such contracts
- 3 as may be necessary to fulfill its duties and responsibilities
- 4 under the Saving the Cure Act; and
- 5 (k) To report annually in December to the Governor and
- 6 the Clerk of the Legislature concerning the activities of the
- 7 commission with recommendations for any legislative changes or
- 8 funding necessary or desirable to fulfill the goals of the act.
- 9 (2) The commission shall provide for protection from
- 10 disclosure of the identity of persons making donations to the
- 11 Nebraska Newborn Umbilical Cord Blood Network.
- 12 <u>(3) The commission may request additional funding from</u>
- 13 any additional source including, but not limited to, federal and
- 14 private grants.
- 15 (4) The commission may establish a foundation for
- 16 purposes of accepting donations of funds to support the Nebraska
- 17 Newborn Umbilical Cord Blood Network.
- 18 Sec. 7. The Saving the Cure Fund is created. The fund
- 19 shall contain amounts appropriated by the Legislature, revenue
- 20 received from gifts, grants, bequests, or other contributions from
- 21 public or private sources. The commission shall use the money in
- 22 the fund to develop and operate the Nebraska Newborn Umbilical Cord
- 23 Blood Network established in section 4 of this act and to carry
- 24 out its duties under section 6 of this act. Any money in the fund
- 25 available for investment shall be invested by the state investment

1 officer pursuant to the Nebraska Capital Expansion Act and the

- 2 Nebraska State Funds Investment Act.
- 3 Sec. 8. After July 1, 2009, the University of Nebraska
- 4 Medical Center may develop, staff, and maintain an accredited
- 5 laboratory to conduct postnatal tissue and fluid research and stem
- 6 cell research. For purposes of this section, (1) postnatal tissue
- 7 and fluid has the definition found in section 3 of this act and (2)
- 8 stem cells has the definition found in such section.
- 9 Sec. 9. Section 71-7611, Revised Statutes Supplement,
- 10 2007, is amended to read:
- 11 71-7611 (1) The Nebraska Health Care Cash Fund is
- 12 created. The State Treasurer shall transfer (a) for fiscal years
- 13 prior to FY2009-10 and each fiscal year thereafter, fifty-five
- 14 million dollars annually no later than July 15 or (b) if a
- 15 laboratory is proposed, developed, staffed, or maintained pursuant
- 16 to section 8 of this act, for FY2009-10 and each fiscal year
- 17 thereafter, fifty-five million five hundred thousand dollars
- 18 annually no later than July 15, from the Nebraska Medicaid
- 19 Intergovernmental Trust Fund and the Nebraska Tobacco Settlement
- 20 Trust Fund to the Nebraska Health Care Cash Fund. The state
- 21 investment officer upon consultation with the Nebraska Investment
- 22 Council shall advise the State Treasurer on the amounts to be
- 23 transferred from the Nebraska Medicaid Intergovernmental Trust Fund
- 24 and from the Nebraska Tobacco Settlement Trust Fund under this
- 25 section in order to sustain such transfers in perpetuity. The state

1 investment officer shall report to the Legislature on or before

- 2 October 1 of every even-numbered year on the sustainability of such
- 3 transfers.
- 4 (2) Any money in the Nebraska Health Care Cash Fund
- 5 available for investment shall be invested by the state investment
- 6 officer pursuant to the Nebraska Capital Expansion Act and the
- 7 Nebraska State Funds Investment Act.
- 8 (3) One million dollars in the Nebraska Health Care Cash
- 9 Fund is designated each year for the Autism Treatment Program
- 10 Act for five fiscal years beginning in fiscal year 2007-08 and
- 11 shall be distributed in each fiscal year as follows: (a) First,
- 12 to the Department of Health and Human Services for costs related
- 13 to application and implementation of the waiver; (b) second, to
- 14 the department for other medical costs for children who would
- 15 not otherwise qualify for medicaid except for the waiver; and (c)
- 16 third, the balance to the Autism Treatment Program Cash Fund. The
- 17 State Treasurer shall transfer the balance of the funding to the
- 18 Autism Treatment Program Cash Fund based on the estimated costs
- 19 of administrative and other medical costs as determined by the
- 20 Legislature through the appropriation process. The transfers to
- 21 the Autism Treatment Program Cash Fund in any fiscal year shall
- 22 be contingent upon the receipt of private matching funds under
- 23 the Autism Treatment Program Act, with no less than one dollar of
- 24 private funds received for every two dollars transferred from the
- 25 Nebraska Health Care Cash Fund to the Autism Treatment Program Cash

- 1 Fund.
- 2 (4) If a laboratory is proposed, developed, staffed, or
- 3 maintained pursuant to section 8 of this act, for FY2009-10 and
- 4 each fiscal year thereafter, the State Treasurer shall distribute
- 5 five hundred thousand dollars from the Nebraska Health Care Cash
- 6 Fund to the University of Nebraska Medical center for the purposes
- 7 provided in section 1 of this act.
- 8 (4) (5) The University of Nebraska and postsecondary
- 9 educational institutions having colleges of medicine in Nebraska
- 10 and their affiliated research hospitals in Nebraska, as a condition
- 11 of receiving any funds appropriated or transferred from the
- 12 Nebraska Health Care Cash Fund, shall not discriminate against
- 13 any person on the basis of sexual orientation.
- 14 Sec. 10. Original section 71-7611, Revised Statutes
- 15 Supplement, 2007, is repealed.