



Substitute Senate Bill No. 152

Public Act No. 11-160

**AN ACT CONCERNING THE ESTABLISHMENT OF THE
CONNECTICUT UMBILICAL CORD BLOOD COLLECTION BOARD.**

Be it enacted by the Senate and House of Representatives in General Assembly convened:

Section 1. (NEW) (*Effective from passage*) Sections 1 to 8, inclusive, of this act shall be known and may be cited as the "Connecticut Umbilical Cord Blood Collection Program Act".

Sec. 2. (NEW) (*Effective from passage*) The General Assembly finds that umbilical cord blood is rich in stem cells that may be used to treat blood cancers, such as leukemia, myeloma and lymphoma, and inherited immunodeficiencies and blood diseases, including sickle cell anemia, thalassemias, hemoglobinopathies, aplastic anemias and marrow failure disorders. Currently, such cord blood is most often discarded as medical waste. As a result, the current inventory of umbilical cord blood is insufficient to meet the medical demand and especially fails to provide matched units for many ethnic and racial groups, including multiethnic individuals. Therefore, the General Assembly declares that it is in the public interest and shall be the public policy of this state to encourage and facilitate the donation, collection and storage of umbilical cord blood and to make such blood units available for medical research and treatment.

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Sec. 3. (NEW) (*Effective from passage*) (a) There is established the Connecticut Umbilical Cord Blood Collection Board. The board shall not be construed to be a department, institution, agency or political subdivision of the state.

(b) The powers of the board shall be vested in and exercised by the following members:

(1) One appointed by the Governor, who shall be a medical director or chief scientist with knowledge of umbilical cord blood banking and affiliated with an entity that is recognized by the Department of Public Health;

(2) One appointed by the speaker of the House of Representatives, who shall be a licensed physician with experience in transplanting units of umbilical cord blood or other stem cells;

(3) One appointed by the president pro tempore of the Senate, who shall be a licensed physician who: (A) Has expertise and is currently practicing in obstetrics, (B) practices at a birthing hospital that participates in umbilical cord blood collection, and (C) is affiliated with a private university hospital;

(4) One appointed by the majority leader of the House of Representatives, who shall be a licensed physician who: (A) Has expertise and is currently practicing in obstetrics, (B) practices at a birthing hospital that participates in umbilical cord blood collection, and (C) is affiliated with a public university hospital;

(5) One appointed by the minority leader of the House of Representatives, who shall be a licensed physician who: (A) Has expertise and is currently practicing in obstetrics, and (B) practices at a birthing hospital that participates in umbilical cord blood collection;

(6) One appointed by the majority leader of the Senate, who shall be

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a member of a nonprofit umbilical cord blood foundation with knowledge of umbilical cord blood banking issues;

(7) One appointed by the minority leader of the Senate, who shall have expertise concerning the regulatory practices of the federal Food and Drug Administration and the federal Health Resources and Services Administration; and

(8) The Commissioner of Public Health, or the commissioner's designee.

(c) All initial appointments to the board shall be made on or before October 1, 2011. The member appointed by the Governor shall serve at the pleasure of the Governor but not longer than the term of office of the Governor or until the member's successor is appointed and has qualified, whichever term is longer. Each board member appointed by a member of the General Assembly shall serve in accordance with the provisions of section 4-1a of the general statutes. The Governor shall fill any vacancy for the unexpired term of a member appointed by the Governor. The appropriate legislative appointing authority shall fill any vacancy for the unexpired term of a member appointed by such authority. Any member shall be eligible for reappointment.

(d) The chairperson of the board shall be appointed by the Governor from among the members of the board. The chairperson shall schedule the first meeting of the board, which shall be held not later than November 1, 2011. Thereafter, meetings of the board shall be held quarterly and at such other time or times as the chairperson deems necessary.

(e) Appointed members may not designate a representative to perform in their absence their respective duties under this section. Any appointed member who fails to attend three consecutive meetings of the board or who fails to attend fifty per cent of all meetings of the

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board held during any calendar year shall be deemed to have resigned from the board. The appointing authority for any member may remove such member for inefficiency, neglect of duty or misconduct in office after giving the member a written copy of the charges against the member and an opportunity to be heard, in person or by counsel, in the member's defense, upon not less than ten days' notice. If any member shall be so removed, the appointing authority for such member shall file in the office of the Secretary of the State a complete statement of charges made against such member and the appointing authority's findings on such statement of charges, together with a complete record of the proceedings.

(f) All members other than the Commissioner of Public Health may engage in private employment, or in a profession or business, subject to any applicable laws, rules and regulations of the state or federal government regarding official ethics or conflict of interest.

(g) Five members of the board shall constitute a quorum for the transaction of any business or the exercise of any power of the board. For the transaction of any business or the exercise of any power of the board, the board may act by a majority of the members present at any meeting at which a quorum is in attendance.

(h) The board may consult with such parties, public or private, as it deems desirable in exercising its duties.

(i) The board may adopt written policies and procedures to carry out its statutory purposes.

(j) Notwithstanding any provision of the general statutes, it shall not constitute a conflict of interest for a trustee, director, partner or officer of any person, firm or corporation, or any individual having a financial interest in a person, firm or corporation, to serve as a member of the board, provided such trustee, director, partner, officer or individual

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shall abstain from deliberation, action or vote by the board in specific respect to such person, firm or corporation.

Sec. 4. (NEW) (*Effective from passage*) (a) The purpose of the Connecticut Umbilical Cord Blood Collection Board is to establish, on or before July 1, 2012, the umbilical cord blood collection program and thereafter administer the program. The umbilical cord blood collection program shall facilitate and promote the collection of units of umbilical cord blood from genetically diverse donors for public use. As used in this subsection, "public use" means (1) use of umbilical cord blood units by state, national and international cord blood registries and transplant centers in order to increase the likelihood of providing suitably matched donor umbilical cord blood units to patients in need of such units or research participants who are in need of a transplant, (2) biological research and new clinical use of stem cells derived from the blood and tissue of the umbilical cord, and (3) medical research that utilizes umbilical cord blood units that could not otherwise be used for transplantation or clinical use.

(b) In order to carry out its statutory purpose, the board may raise funds, apply for and accept any public or private grant money, accept contributions, enter into contracts and, within available resources, hire any necessary staff, including, but not limited to, an executive director.

Sec. 5. (NEW) (*Effective from passage*) (a) In order to achieve the umbilical cord blood collection goals of the program, the board shall, commensurate with available funds appropriated for the administration of the program, contract with one or more entities that have demonstrated the competence to collect and transport umbilical cord blood units in compliance with all applicable federal law and who meet all other requirements prescribed in this section. The board shall contract to establish or designate not less than two umbilical cord blood collection centers at fixed locations in the state. Any such fixed location collection center shall be located at a birthing hospital with

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three thousand seven hundred fifty or more births per year and where a disproportionate share of such births involve women from minority populations. The board shall, to the extent practicable, encourage the collection of units of umbilical cord blood at other nonfixed locations in the state as is practicable.

(b) Any contract entered into pursuant to subsection (a) of this section shall: (1) Use a competitive process that identifies the best proposals submitted by applicant entities to achieve the collection and research objectives of the program; and (2) provide that (A) the state retains an interest in any umbilical cord blood collected in the state commensurate with its investment in the program, (B) income received by the board as a result of the contract shall be used to ensure that the umbilical cord blood collection program shall be self-sustaining not later than July 1, 2020, (C) any units of umbilical cord blood deemed unsuitable for transplantation shall be returned to the state for use in biological or medical research, and (D) any entity with whom the board contracts shall provide quarterly reports to the board that include, but are not limited to, information concerning: (i) The total number of umbilical cord blood units collected, (ii) the number of collected units deemed suitable for transplant, (iii) the number of collected units deemed suitable for research only, and (iv) the clinical outcomes of any transplanted units. Reports provided to the board pursuant to this subsection shall not include personally identifiable information.

(c) Any entity seeking to enter into a contract with the board shall, at a minimum, be in compliance with the requirements of the federal Food and Drug Administration pertaining to the manufacture of clinical-grade cord blood stem cell units for clinical indications.

(d) Any medical facility or research facility performing services on behalf of the board, pursuant to a contract entered into pursuant to subsection (a) of this section, shall comply with, and be subject to, state

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and federal law concerning the protection of medical information and personally identifiable information contained in, or obtained through, the umbilical cord blood collection inventory.

(e) For purposes of this section and section 4 of this act, the board shall not be considered a "state contracting agency", as defined in subdivision (28) of section 4e-1 of the general statutes.

Sec. 6. (NEW) (*Effective from passage*) There is established an account to be known as the "Umbilical Cord Blood Collection Account" which shall be a separate, nonlapsing account within the General Fund. The account may contain any moneys required or permitted by law to be deposited in the account and any moneys received from any public or private contributions, gifts, grants, donations, bequests or devises to the account. The Connecticut Umbilical Cord Blood Collection Board may expend moneys from the account as is necessary to carry out the board's statutory purpose established by this act.

Sec. 7. (NEW) (*Effective from passage*) The members of the Connecticut Umbilical Cord Blood Collection Board shall submit to the joint standing committees of the General Assembly having cognizance of matters relating to public health and appropriations and the budgets of state agencies a copy of any audit of the board conducted by an independent auditing firm, not later than seven days after the audit is received by the board.

Sec. 8. (NEW) (*Effective from passage*) On or before January 1, 2012, and quarterly thereafter, the Connecticut Umbilical Cord Blood Collection Board shall report to the Governor and the joint standing committees of the General Assembly having cognizance of matters relating to public health and appropriations and the budgets of state agencies, in accordance with the provisions of section 11-4a of the general statutes, on the status and effectiveness of the umbilical cord blood collection program.

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Sec. 9. Section 19a-32n of the general statutes is repealed and the following is substituted in lieu thereof (*Effective from passage*):

(a) A physician or other health care provider who provides health care services to a pregnant woman during the last trimester of her pregnancy, which health care services are directly related to her pregnancy, shall provide the woman with timely, relevant and appropriate information sufficient to allow her to make an informed and voluntary choice regarding options to bank or donate umbilical cord blood following the delivery of a newborn child.

(b) The Connecticut Umbilical Cord Blood Collection Board, established pursuant to section 3 of this act, shall, within available appropriations, engage in public education and marketing activities that promote and raise awareness among physicians and pregnant women of the umbilical cord blood collection program established pursuant to section 4 of this act.

Approved July 13, 2011