



Sen. Jeffrey M. Schoenberg

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1 AMENDMENT TO SENATE BILL 1324

2 AMENDMENT NO. _____. Amend Senate Bill 1324 by replacing
3 everything after the enacting clause with the following:

4 "Section 5. If and only if Senate Bill 19 of the 95th
5 General Assembly, as engrossed, becomes law, then the
6 Department of Public Health Powers and Duties Law of the Civil
7 Administrative Code of Illinois is amended by changing Section
8 2310-577 as follows:

9 (20 ILCS 2310/2310-577)

10 Sec. 2310-577. Cord blood stem cell banks.

11 (a) Subject to appropriation, the Department shall
12 establish a ~~statewide~~ network of human cord blood stem cell
13 banks. The Director shall enter into contracts with qualified
14 cord blood stem cell banks to assist in the establishment,
15 provision, and maintenance of the network.

16 (b) A cord blood stem cell bank is eligible to enter the

1 network and be a donor bank if it satisfies each of the
2 following:

3 (1) Has obtained all applicable federal and State
4 licenses, accreditations, certifications, registrations,
5 and other authorizations required to operate and maintain a
6 cord blood stem cell bank.

7 (2) Has implemented donor screening and cord blood
8 collection practices adequate to protect both donors and
9 transplant recipients and to prevent transmission of
10 potentially harmful infections and other diseases.

11 (3) Has established a system of strict confidentiality
12 to protect the identity and privacy of patients and donors
13 in accordance with existing federal and State law and
14 consistent with regulations promulgated under the Health
15 Insurance Portability and Accountability Act of 1996,
16 Public Law 104-191, for the release of the identity of
17 donors, the identity of recipients, or identifiable
18 records.

19 (4) Has established a system for encouraging donation
20 by an ethnically and racially diverse group of donors.

21 (5) Has developed adequate systems for communication
22 with other cord blood stem cell banks, transplant centers,
23 and physicians with respect to the request, release, and
24 distribution of cord blood units nationally and has
25 developed those systems, consistent with the regulations
26 promulgated under the Health Insurance Portability and

1 Accountability Act of 1996, Public Law 104-191, to track
2 recipients' clinical outcomes for distributed units.

3 (6) Has developed an objective system for educating the
4 public, including patient advocacy organizations, about
5 the benefits of donating and utilizing cord blood stem
6 cells in appropriate circumstances.

7 (7) Has policies and procedures in place for the
8 procurement of materials for the conduct of stem cell
9 research, including policies and procedures ensuring that
10 persons are empowered to make voluntary and informed
11 decisions to participate or to refuse to participate in the
12 research, and ensuring confidentiality of the decision.

13 (8) Has policies and procedures in place to ensure the
14 bank is following current best practices with respect to
15 medical ethics, including informed consent of patients and
16 the protection of human subjects.

17 (c) A donor bank that enters into the network shall do all
18 of the following:

19 (1) Acquire, tissue-type, test, cryopreserve, and
20 store donated units of human cord blood acquired with the
21 informed consent of the donor, in a manner that complies
22 with applicable federal regulations.

23 (2) Make cord blood units collected under this Section,
24 or otherwise, available to transplant centers for stem cell
25 transplantation.

26 (3) Allocate up to 10% of the cord blood inventory each

1 year for peer-reviewed research. This quota may be met by
2 using cord blood units that did not meet the cell count
3 standards necessary for transplantation.

4 (d) An advisory committee shall advise the Department
5 concerning the administration of the State cord blood stem cell
6 bank network. The committee shall be appointed by the Director
7 and consist of members who represent each of the following:

8 (1) Cord blood stem cell transplant centers.

9 (2) Physicians from participating birthing hospitals.

10 (3) The cord blood stem cell research community.

11 (4) Recipients of cord blood stem cell transplants.

12 (5) Family members who have made a donation to a
13 statewide cord blood stem cell bank.

14 (6) Individuals with expertise in the social sciences.

15 (7) Members of the general public.

16 (8) Each network donor bank.

17 Except as otherwise provided under this subsection, each
18 member of the committee shall serve for a 3-year term and may
19 be reappointed for one or more additional terms. Appointments
20 for the initial members shall be for terms of 1, 2, and 3
21 years, respectively, so as to provide for the subsequent
22 appointment of an equal number of members each year. The
23 committee shall elect a chairperson.

24 (d-1) A person has a conflict of interest if any action,
25 advice, or recommendation with respect to a matter may directly
26 or indirectly financially benefit any of the following:

1 (1) That person.

2 (2) That person's spouse, immediate family living with
3 that person, or that person's extended family.

4 (3) Any individual or entity required to be disclosed
5 by that person.

6 (4) Any other individual or entity with which that
7 person has a business or professional relationship.

8 An advisory committee member who has a conflict of interest
9 with respect to a matter may not discuss that matter with other
10 committee members and shall not vote upon or otherwise
11 participate in any committee action, advice, or recommendation
12 with respect to that matter. Each recusal occurring during a
13 committee meeting shall be made a part of the minutes or
14 recording of the meeting in accordance with the Open Meetings
15 Act.

16 The Department shall not allow any Department employee to
17 participate in the processing of, or to provide any advice or
18 recommendation concerning, any matter with which the
19 Department employee has a conflict of interest.

20 (d-2) Each advisory committee member shall file with the
21 Secretary of State a written disclosure of the following with
22 respect to the member, the member's spouse, and any immediate
23 family living with the member:

24 (1) Each source of income.

25 (2) Each entity in which the member, spouse, or
26 immediate family living with the member has an ownership or

1 distributive income share that is not an income source
2 required to be disclosed under item (1) of this subsection
3 (d-2).

4 (3) Each entity in or for which the member, spouse, or
5 immediate family living with the member serves as an
6 executive, officer, director, trustee, or fiduciary.

7 (4) Each entity with which the member, member's spouse,
8 or immediate family living with the member has a contract
9 for future income.

10 Each advisory committee member shall file the disclosure
11 required by this subsection (d-2) at the time the member is
12 appointed and at the time of any reappointment of that member.

13 Each advisory committee member shall file an updated
14 disclosure with the Secretary of State promptly after any
15 change in the items required to be disclosed under this
16 subsection with respect to the member, the member's spouse, or
17 any immediate family living with the member.

18 The requirements of Section 3A-30 of the Illinois
19 Governmental Ethics Act and any other disclosures required by
20 law apply to this Act.

21 Filed disclosures shall be public records.

22 (e) The Department shall do each of the following:

23 (1) Ensure that the donor banks within the network meet
24 the requirements of subsection (b) on a continuing basis.

25 (2) Encourage network donor banks to work
26 collaboratively with other network donor banks and

1 encourage network donor banks to focus their resources in
2 their respective local or regional area.

3 (3) Designate one or more established national or
4 international cord blood registries to serve as a statewide
5 cord blood stem cell registry.

6 (4) Coordinate the donor banks in the network.

7 In performing these duties, the Department may seek the
8 advice of the advisory committee.

9 (f) Definitions. As used in this Section:

10 (1) "Cord blood unit" means the blood collected from a
11 single placenta and umbilical cord.

12 (2) "Donor" means a mother who has delivered a baby and
13 consents to donate the newborn's blood remaining in the
14 placenta and umbilical cord.

15 (3) "Donor bank" means a qualified cord blood stem cell
16 bank that enters into a contract with the Director under
17 this Section.

18 (4) "Human cord blood stem cells" means hematopoietic
19 stem cells and any other stem cells contained in the
20 neonatal blood collected immediately after the birth from
21 the separated placenta and umbilical cord.

22 (5) "Network" means the ~~statewide~~ network of qualified
23 cord blood stem cell banks established under this Section.

24 (Source: 95SB0019eng.)

25 Section 99. Effective date. This Act takes effect upon

1 becoming law.".