



Human Services Committee

Filed: 5/16/2007

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LRB095 06541 RCE 36003 a

1 AMENDMENT TO SENATE BILL 19

2 AMENDMENT NO. \_\_\_\_\_. Amend Senate Bill 19 by replacing  
3 everything after the enacting clause with the following:

4 "Section 5. The Department of Public Health Powers and  
5 Duties Law of the Civil Administrative Code of Illinois is  
6 amended by adding Section 2310-577 as follows:

7 (20 ILCS 2310/2310-577 new)

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

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

14 (b) A cord blood stem cell bank is eligible to enter the  
15 network and be a donor bank if it satisfies each of the  
16 following:

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

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

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

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

19           (5) Has developed adequate systems for communication  
20           with other cord blood stem cell banks, transplant centers,  
21           and physicians with respect to the request, release, and  
22           distribution of cord blood units nationally and has  
23           developed those systems, consistent with the regulations  
24           promulgated under the Health Insurance Portability and  
25           Accountability Act of 1996, Public Law 104-191, to track  
26           recipients' clinical outcomes for distributed units.

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

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

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

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

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

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

24           (3) Allocate up to 10% of the cord blood inventory each  
25           year for peer-reviewed research. This quota may be met by  
26           using cord blood units that did not meet the cell count

1       standards necessary for transplantation.

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

6           (1) Cord blood stem cell transplant centers.

7           (2) Physicians from participating birthing hospitals.

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

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

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

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

13          (7) Members of the general public.

14          (8) Each network donor bank.

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

22       (e) A person has a conflict of interest if any action,  
23 advice, or recommendation with respect to a matter may directly  
24 or indirectly financially benefit any of the following:

25           (1) That person.

26           (2) That person's spouse, immediate family living with

1       that person, or that person's extended family.

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

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

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

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

18       (f) Each advisory committee member shall file with the  
19       Secretary of State a written disclosure of the following with  
20       respect to the member, the member's spouse, and any immediate  
21       family living with the member:

22           (1) Each source of income.

23           (2) Each entity in which the member, spouse, or  
24       immediate family living with the member has an ownership or  
25       distributive income share that is not an income source  
26       required to be disclosed under item (1) of this subsection

1       (f).

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

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

8           Each advisory committee member shall file the disclosure  
9           required by this subsection (f) at the time the member is  
10          appointed and at the time of any reappointment of that member.

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

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

19          Filed disclosures shall be public records.

20          (g) The Department shall do each of the following:

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

23           (2) Encourage network donor banks to work  
24           collaboratively with other network donor banks and  
25           encourage network donor banks to focus their resources in  
26           their respective local or regional area.

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

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

5           In performing these duties, the Department may seek the  
6           advice of the advisory committee.

7           (h) Definitions. As used in this Section:

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

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

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

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

20           (5) "Network" means the network of qualified cord blood  
21           stem cell banks established under this Section.

22           Section 99. Effective date. This Act takes effect upon  
23           becoming law."