

1 AN ACT concerning stem cell research.

2 **Be it enacted by the People of the State of Illinois,**
3 **represented in the General Assembly:**

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
17 network and be a donor bank if it satisfies each of the
18 following:

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

23 (2) Has implemented donor screening and cord blood

1 collection practices adequate to protect both donors and
2 transplant recipients and to prevent transmission of
3 potentially harmful infections and other diseases.

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

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

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

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

26 (7) Has policies and procedures in place for the

1 procurement of materials for the conduct of stem cell
2 research, including policies and procedures ensuring that
3 persons are empowered to make voluntary and informed
4 decisions to participate or to refuse to participate in the
5 research, and ensuring confidentiality of the decision.

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

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

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

16 (2) Make cord blood units collected under this Section,
17 or otherwise, available to transplant centers for stem cell
18 transplantation.

19 (3) Allocate up to 10% of the cord blood inventory each
20 year for peer-reviewed research. This quota may be met by
21 using cord blood units that did not meet the cell count
22 standards necessary for transplantation.

23 (d) An advisory committee shall advise the Department
24 concerning the administration of the ~~State~~ cord blood stem cell
25 bank network. The committee shall be appointed by the Director
26 and consist of members who represent each of the following:

- 1 (1) Cord blood stem cell transplant centers.
- 2 (2) Physicians from participating birthing hospitals.
- 3 (3) The cord blood stem cell research community.
- 4 (4) Recipients of cord blood stem cell transplants.
- 5 (5) Family members who have made a donation to a
6 statewide cord blood stem cell bank.
- 7 (6) Individuals with expertise in the social sciences.
- 8 (7) Members of the general public.
- 9 (8) Each network donor bank.

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

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

- 20 (1) That person.
- 21 (2) That person's spouse, immediate family living with
22 that person, or that person's extended family.
- 23 (3) Any individual or entity required to be disclosed
24 by that person.
- 25 (4) Any other individual or entity with which that
26 person has a business or professional relationship.

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

9 The Department shall not allow any Department employee to
10 participate in the processing of, or to provide any advice or
11 recommendation concerning, any matter with which the
12 Department employee has a conflict of interest.

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

17 (1) Each source of income.

18 (2) Each entity in which the member, spouse, or
19 immediate family living with the member has an ownership or
20 distributive income share that is not an income source
21 required to be disclosed under item (1) of this subsection
22 (d-2).

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

26 (4) Each entity with which the member, member's spouse,

1 or immediate family living with the member has a contract
2 for future income.

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

6 Each advisory committee member shall file an updated
7 disclosure with the Secretary of State promptly after any
8 change in the items required to be disclosed under this
9 subsection with respect to the member, the member's spouse, or
10 any immediate family living with the member.

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

14 Filed disclosures shall be public records.

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

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

18 (2) Encourage network donor banks to work
19 collaboratively with other network donor banks and
20 encourage network donor banks to focus their resources in
21 their respective local or regional area.

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

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

26 In performing these duties, the Department may seek the

1 advice of the advisory committee.

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

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

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

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

11 (4) "Human cord blood stem cells" means hematopoietic
12 stem cells and any other stem cells contained in the
13 neonatal blood collected immediately after the birth from
14 the separated placenta and umbilical cord.

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

17 (Source: 95SB0019eng.)

18 Section 99. Effective date. This Act takes effect upon
19 becoming law.