SB0019 Enrolled

AN ACT concerning public health. 1

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

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

7 (20 ILCS 2310/2310-577 new)

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

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

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

17 (1) Has obtained all applicable federal and State licenses, accreditations, certifications, registrations, 18 19 and other authorizations required to operate and maintain a 20 cord blood stem cell bank.

21 (2) Has implemented donor screening and cord blood 22 collection practices adequate to protect both donors and transplant recipients and to prevent transmission of 23

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potentially harmful infections and other diseases. 1 2 (3) Has established a system of strict confidentiality 3 to protect the identity and privacy of patients and donors in accordance with existing federal and State law and 4 5 consistent with regulations promulgated under the Health Insurance Portability and Accountability Act of 1996, 6 7 Public Law 104-191, for the release of the identity of 8 donors, the identity of recipients, or identifiable 9 records. 10 (4) Has established a system for encouraging donation 11 by an ethnically and racially diverse group of donors. 12 (5) Has developed adequate systems for communication with other cord blood stem cell banks, transplant centers, 13 14 and physicians with respect to the request, release, and distribution of cord blood units nationally and has 15 developed those systems, consistent with the regulations 16 promulgated under the Health Insurance Portability and 17 Accountability Act of 1996, Public Law 104-191, to track 18 19 recipients' clinical outcomes for distributed units. 20 (6) Has developed an objective system for educating the 21 public, including patient advocacy organizations, about 22 the benefits of donating and utilizing cord blood stem 23 cells in appropriate circumstances. 24 (7) Has policies and procedures in place for the 25 procurement of materials for the conduct of stem cell 26 research, including policies and procedures ensuring that

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persons are empowered to make voluntary and informed 1 2 decisions to participate or to refuse to participate in the 3 research, and ensuring confidentiality of the decision. (8) Has policies and procedures in place to ensure the 4 5 bank is following current best practices with respect to medical ethics, including informed consent of patients and 6 7 the protection of human subjects. 8 (c) A donor bank that enters into the network shall do all 9 of the following: 10 (1) Acquire, tissue-type, test, cryopreserve, and 11 store donated units of human cord blood acquired with the 12 informed consent of the donor, in a manner that complies with applicable federal regulations. 13 14 (2) Make cord blood units collected under this Section, 15 or otherwise, available to transplant centers for stem cell 16 transplantation. (3) Allocate up to 10% of the cord blood inventory each 17 year for peer-reviewed research. This quota may be met by 18 19 using cord blood units that did not meet the cell count 20 standards necessary for transplantation. 21 (4) Make agreements with obstetrical health care 22 facilities, consistent with federal regulations, for the 23 collection of donated units of human cord blood. 24 (d) An advisory committee shall advise the Department 25 concerning the administration of the cord blood stem cell bank network. The committee shall be appointed by the Director and 26

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1	consist of members who represent each of the following:
2	(1) Cord blood stem cell transplant centers.
3	(2) Physicians from participating birthing hospitals.
4	(3) The cord blood stem cell research community.
5	(4) Recipients of cord blood stem cell transplants.
6	(5) Family members who have made a donation to a
7	statewide cord blood stem cell bank.
8	(6) Individuals with expertise in the social sciences.
9	(7) Members of the general public.
10	(8) Each network donor bank.
11	(9) Hospital administration from birthing hospitals.
12	Except as otherwise provided under this subsection, each
13	member of the committee shall serve for a 3-year term and may
14	be reappointed for one or more additional terms. Appointments
15	for the initial members shall be for terms of 1, 2, and 3
16	years, respectively, so as to provide for the subsequent
17	appointment of an equal number of members each year. The
18	committee shall elect a chairperson.
19	(e) A person has a conflict of interest if any action,
20	advice, or recommendation with respect to a matter may directly
21	or indirectly financially benefit any of the following:
22	(1) That person.
23	(2) That person's spouse, immediate family living with
24	that person, or that person's extended family.
25	(3) Any individual or entity required to be disclosed
26	by that person.

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(4) Any other individual or entity with which that
person has a business or professional relationship.
An advisory committee member who has a conflict of interest
with respect to a matter may not discuss that matter with other
committee members and shall not vote upon or otherwise
participate in any committee action, advice, or recommendation
with respect to that matter. Each recusal occurring during a
committee meeting shall be made a part of the minutes or
recording of the meeting in accordance with the Open Meetings
<u>Act.</u>
The Department shall not allow any Department employee to
participate in the processing of, or to provide any advice or
recommendation concerning, any matter with which the
Department employee has a conflict of interest.
(f) Each advisory committee member shall file with the
Secretary of State a written disclosure of the following with
respect to the member, the member's spouse, and any immediate
family living with the member:
(1) Each source of income.
(2) Each entity in which the member, spouse, or
immediate family living with the member has an ownership or
distributive income share that is not an income source
required to be disclosed under item (1) of this subsection
<u>(f).</u>
(3) Each entity in or for which the member, spouse, or
immediate family living with the member serves as an

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1	executive, officer, director, trustee, or fiduciary.
2	(4) Each entity with which the member, member's spouse,
3	or immediate family living with the member has a contract
4	for future income.
5	Each advisory committee member shall file the disclosure
6	required by this subsection (f) at the time the member is
7	appointed and at the time of any reappointment of that member.
8	Each advisory committee member shall file an updated
9	disclosure with the Secretary of State promptly after any
10	change in the items required to be disclosed under this
11	subsection with respect to the member, the member's spouse, or
12	any immediate family living with the member.
13	The requirements of Section 3A-30 of the Illinois
14	Governmental Ethics Act and any other disclosures required by
15	law apply to this Act.
16	Filed disclosures shall be public records.
17	(g) The Department shall do each of the following:
18	(1) Ensure that the donor banks within the network meet
19	the requirements of subsection (b) on a continuing basis.
20	(2) Encourage network donor banks to work
21	collaboratively with other network donor banks and
22	encourage network donor banks to focus their resources in
23	their respective local or regional area.
24	(3) Designate one or more established national or
25	international cord blood registries to serve as a statewide
26	cord blood stem cell registry.

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1	(4) Coordinate the donor banks in the network.
2	In performing these duties, the Department may seek the
3	advice of the advisory committee.
4	(h) Definitions. As used in this Section:
5	(1) "Cord blood unit" means the blood collected from a
6	single placenta and umbilical cord.
7	(2) "Donor" means a mother who has delivered a baby and
8	consents to donate the newborn's blood remaining in the
9	placenta and umbilical cord.
10	(3) "Donor bank" means a qualified cord blood stem cell
11	bank that enters into a contract with the Director under
12	this Section.
13	(4) "Human cord blood stem cells" means hematopoietic
14	stem cells and any other stem cells contained in the
15	neonatal blood collected immediately after the birth from
16	the separated placenta and umbilical cord.
17	(5) "Network" means the network of qualified cord blood
18	stem cell banks established under this Section.
19	Section 99. Effective date. This Act takes effect upon

20 becoming law.