

SECOND REGULAR SESSION

# HOUSE BILL NO. 2117

## 93RD GENERAL ASSEMBLY

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INTRODUCED BY REPRESENTATIVES POLLOCK (Sponsor), LEMBKE, EMERY, PHILLIPS, COOPER (155), SATER, WILSON (119), WELLS, YAEGER, SANDER, CUNNINGHAM (86), DIXON, WRIGHT-JONES, PARKER, BOYKINS, HARRIS (110) AND FAITH (Co-sponsors).

Read 1st time March 30, 2006 and copies ordered printed.

STEPHEN S. DAVIS, Chief Clerk

5126L.01I

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### AN ACT

To amend chapter 191, RSMo, by adding thereto one new section relating to an umbilical cord blood bank program.

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*Be it enacted by the General Assembly of the state of Missouri, as follows:*

Section A. Chapter 191, RSMo, is amended by adding thereto one new section, to be  
2 known as section 191.275, to read as follows:

191.275. 1. Beginning January 1, 2007, the department of health and senior  
2 services shall, subject to appropriations, establish the "Umbilical Cord Blood Bank Service  
3 Program" to gather, collect, and preserve umbilical cord blood only from live births and  
4 provide such blood and blood components to persons and institutions conducting scientific  
5 research requiring sources of human stem cells.

6 2. The department may contract with any public or private umbilical cord blood  
7 bank service within and/or outside the state of Missouri to store umbilical cord blood for  
8 distribution to researchers upon request and as authorized by the department of health  
9 and senior services. Nothing in this section shall prohibit any umbilical cord blood bank  
10 service from informing potential donors of the benefits of private banking of umbilical  
11 cord blood in lieu of participation in the program.

12 3. Under the program, the department shall, whenever possible, attempt to reserve  
13 twenty percent of any umbilical cord blood gathered, collected, and preserved for possible

EXPLANATION — Matter enclosed in bold-faced brackets [thus] in the above bill is not enacted and is intended to be omitted from the law. Matter in **bold-face** type in the above bill is proposed language.

14 future use by the donor child. Nothing in this subsection shall be construed as imposing  
15 any civil or criminal liability for the department, any umbilical cord blood bank service,  
16 or researcher for failure to maintain the suggested umbilical cord blood reserves.

17 **4. The department shall promulgate rules for the implementation of the program,**  
18 **including but not limited to rules for the following:**

19 **(1) A public awareness campaign to inform prospective umbilical cord donors of**  
20 **the opportunity to donate umbilical cord blood and the benefits of such donation. Such**  
21 **campaign shall include preparation and distribution of pamphlets and other literature on**  
22 **the program. Any umbilical cord blood bank service may request the department to**  
23 **include a telephone number or other contact information in such pamphlets or other**  
24 **literature regarding the availability of private banking of umbilical cord blood. The**  
25 **department shall include such contact information in pamphlets and other literature upon**  
26 **request of any umbilical cord blood bank service;**

27 **(2) Utilization of licensed health care providers and facilities throughout the state**  
28 **to make the pamphlets and other literature on the program available to the public.**  
29 **Nothing in this subdivision shall be construed as requiring any health care provider or**  
30 **facility to inform or otherwise discuss the program with any patient in any manner other**  
31 **than to make the department's pamphlets and other literature available;**

32 **(3) The questions to be asked of potential donors, including but not limited to the**  
33 **following:**

34 **(a) Inquiring on whether the potential donor is willing to donate umbilical cord**  
35 **blood for the program; and**

36 **(b) If a potential donor agrees to donate umbilical cord blood for the program,**  
37 **whether the name of the donor child may be recorded for data collection and research**  
38 **purposes, and to provide the services listed in subdivision (5) of this subsection;**

39 **(4) Establishing an identification numbering system for umbilical cord blood**  
40 **gathered, collected, and preserved under the program. Each umbilical cord donated under**  
41 **the program shall be assigned a unique identification number and shall be the sole means**  
42 **of identifying and tracking the donation under the program. The department shall**  
43 **maintain in the records of the program the donor child's name associated with each**  
44 **identification number. The donor child's name shall be confidential and not subject to**  
45 **disclosure by the department under chapter 610, RSMo;**

46 **(5) Establish a system for providing the donor child, upon request of the child or**  
47 **the child's parent or legal guardian, with access to any identifying information, reserved**  
48 **umbilical cord blood, or research results based on any research conducted utilizing such**  
49 **child's umbilical cord blood. Nonidentifying information shall be made available to any**

50 person engaged in bona fide research purpose, with the permission of the director;  
51 provided, however, that no information identifying the donor child shall be made available  
52 to the researcher unless the identifying information is essential to the research or  
53 evaluation and the child's parent or guardian provides written permission; and

54 (6) Establish the record keeping and reporting requirements for umbilical cord  
55 blood banks and researchers participating in the program.

56 5. Researchers obtaining umbilical cord blood under the program shall enter into  
57 a contract with the department under which each researcher agrees to:

58 (1) Make any research results specific to a particular donor available to a donor  
59 child upon request; and

60 (2) Comply with any record keeping and reporting requirements imposed by the  
61 department.

62 6. Any rule or portion of a rule, as that term is defined in section 536.010, RSMo,  
63 that is created under the authority delegated in this section shall become effective only if  
64 it complies with and is subject to all of the provisions of chapter 536, RSMo, and, if  
65 applicable, section 536.028, RSMo. This section and chapter 536, RSMo, are nonseverable  
66 and if any of the powers vested with the general assembly pursuant to chapter 536, RSMo,  
67 to review, to delay the effective date, or to disapprove and annul a rule are subsequently  
68 held unconstitutional, then the grant of rulemaking authority and any rule proposed or  
69 adopted after August 28, 2006, shall be invalid and void.

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