

4171--B

2015-2016 Regular Sessions

I N A S S E M B L Y

January 29, 2015

Introduced by M. of A. WRIGHT, GUNTHER, PICHARDO, KAMINSKY -- Multi-Sponsored by -- M. of A. PALMESANO, PEOPLES-STOKES, PERRY, RA, THIELE -- read once and referred to the Committee on Health -- committee discharged, bill amended, ordered reprinted as amended and recommitted to said committee -- again reported from said committee with amendments, ordered reprinted as amended and recommitted to said committee

AN ACT to amend the public health law, the state finance law and the election law, in relation to providing for the creation and dissemination of information pertaining to bone marrow and peripheral blood stem cell donation and bone marrow and peripheral blood stem cell donation registration

THE PEOPLE OF THE STATE OF NEW YORK, REPRESENTED IN SENATE AND ASSEMBLY, DO ENACT AS FOLLOWS:

1 Section 1. This act shall be known and may be cited as "Jaden's law".
2 S 2. Subdivision 1 of section 207 of the public health law is amended
3 by adding a new paragraph (l) to read as follows:
4 (L) BONE MARROW AND PERIPHERAL BLOOD STEM CELL DONATION.
5 S 3. The public health law is amended by adding a new section 4369 to
6 read as follows:
7 S 4369. BONE MARROW AND PERIPHERAL BLOOD STEM CELL INFORMATION. 1. A
8 PHYSICIAN, AS EARLY AS PRACTICABLE IN THE PHYSICIAN'S THERAPEUTIC
9 RELATIONSHIP WITH A PATIENT, AND UNLESS THE PHYSICIAN REASONABLY
10 BELIEVES THAT BONE MARROW OR PBSC DONATION WOULD THREATEN THE HEALTH OF
11 THE PATIENT, MAY PROVIDE A COPY OF THE BROCHURE PREPARED BY THE COMMIS-
12 SIONER TO EVERY PATIENT:
13 (A) WHO IS KNOWN BY THE PHYSICIAN TO BE AT LEAST EIGHTEEN YEARS OF AGE
14 BUT NO OLDER THAN SIXTY YEARS OF AGE; AND
15 (B) WHO THE PHYSICIAN ANTICIPATES WILL BE ADMITTED TO A HOSPITAL FOR
16 AN ELECTIVE ORTHOPEDIC PROCEDURE OR TREATMENT OR OTHERWISE BELIEVES IS
17 AN APPROPRIATE CANDIDATE FOR BONE MARROW OR PBSC DONATION; OR FOR WHOM
18 THE PHYSICIAN OTHERWISE BELIEVES BONE MARROW OR PBSC DONATION IS APPRO-

EXPLANATION--Matter in *ITALICS* (underscored) is new; matter in brackets [] is old law to be omitted.

LBD05503-04-5

1 PRIATE TO THE PATIENT'S MEDICAL CIRCUMSTANCES OR IS DESIRED BY THE
2 PATIENT.

3 2. THE PHYSICIAN MAY OFFER TO DISCUSS THE INFORMATION CONTAINED IN THE
4 BROCHURE WITH THE PATIENT OR THE PATIENT'S REPRESENTATIVE.

5 3. THIS SECTION SHALL NOT BE CONSTRUED TO APPLY TO A PHYSICIAN WHO IS
6 DIRECTLY AFFILIATED WITH A RELIGIOUS DENOMINATION THAT ADHERES TO THE
7 TENET THAT BONE MARROW OR PBSC TRANSFER IS CONTRARY TO THE MORAL PRINCI-
8 PLES WHICH THE DENOMINATION CONSIDERS TO BE AN ESSENTIAL PART OF ITS
9 BELIEFS AND PRACTICES.

10 S 4. The public health law is amended by adding a new section 4311 to
11 read as follows:

12 S 4311. NEW YORK STATE BONE MARROW AND PERIPHERAL BLOOD STEM CELL
13 DONATION REGISTRY. 1. THE DEPARTMENT SHALL ESTABLISH A BONE MARROW AND
14 PERIPHERAL BLOOD STEM CELL (PBSC) DONATION REGISTRY, TO BE KNOWN AS THE
15 "PBSC REGISTRY", WHICH SHALL PROVIDE A MEANS TO MAKE AND REGISTER A GIFT
16 OF BONE MARROW AND PERIPHERAL BLOOD STEM CELLS TO TAKE PLACE PURSUANT TO
17 THE PROVISIONS OF THIS ARTICLE. THE PBSC REGISTRY SHALL CONTAIN A LIST-
18 ING OF ALL DONORS WHO HAVE DECLARED THEIR CONSENT TO MAKE SUCH ANATOM-
19 ICAL GIFTS.

20 2. THE COMMISSIONER MAY ENTER INTO A MULTI-YEAR CONTRACT FOR THE OPER-
21 ATION AND PROMOTION OF THE PBSC REGISTRY, SUBJECT TO SUCH TERMS AND
22 CONDITIONS AS MAY BE CONTAINED WITHIN SUCH CONTRACT WITH A NOT-FOR-PRO-
23 FIT ORGANIZATION THAT HAS EXPERIENCE WORKING WITH DONATION COMMUNITIES
24 THROUGHOUT THE STATE. THE CONTRACTOR MAY SUBCONTRACT AS NEEDED FOR THE
25 EFFECTIVE PERFORMANCE OF THE CONTRACT. ALL SUCH SUBCONTRACTORS AND THE
26 TERMS OF SUCH SUBCONTRACTS SHALL BE SUBJECT TO APPROVAL BY THE COMMIS-
27 SIONER. ANY APPLICABLE STATE AGENCY, INCLUDING, BUT NOT LIMITED TO, THE
28 DEPARTMENT, THE DEPARTMENT OF MOTOR VEHICLES AND THE BOARD OF ELECTIONS,
29 SHALL COOPERATE IN THE COLLECTION AND TRANSFER OF REGISTRANT DATA TO THE
30 PBSC REGISTRY.

31 3. THE DUTIES OF THE CONTRACTOR SHALL INCLUDE, BUT NOT BE LIMITED TO,
32 THE FOLLOWING:

33 (A) THE DEVELOPMENT, IMPLEMENTATION AND MAINTENANCE OF THE PBSC REGIS-
34 TRY THAT INCLUDES ONLINE, MAILED AND OTHER FORMS OF BONE MARROW AND
35 PERIPHERAL BLOOD STEM CELL DONOR REGISTRATION, VERIFICATION, AMENDMENT
36 AND REVOCATION;

37 (B) PREPARATION AND SUBMISSION OF A PLAN TO ENCOURAGE BONE MARROW AND
38 PERIPHERAL BLOOD STEM CELL DONATION THROUGH EDUCATION AND MARKETING
39 EFFORTS AND OTHER RECOMMENDATIONS THAT WOULD STREAMLINE AND ENHANCE THE
40 COST-EFFECTIVE OPERATION OF THE PBSC REGISTRY;

41 (C) PROVISION OF WRITTEN OR ELECTRONIC NOTIFICATION OF REGISTRATION IN
42 THE PBSC REGISTRY TO AN INDIVIDUAL ENROLLING IN THE PBSC REGISTRY; AND

43 (D) PREPARATION AND SUBMISSION OF AN ANNUAL WRITTEN REPORT TO THE
44 DEPARTMENT. SUCH REPORT SHALL INCLUDE:

45 (I) A PERFORMANCE MATRIX INCLUDING THE NUMBER OF REGISTRANTS ON THE
46 PBSC REGISTRY AND AN ANALYSIS OF THE REGISTRATION RATES, INCLUDING BUT
47 NOT LIMITED TO, LOCATION, METHOD OF REGISTRATION, DEMOGRAPHIC, AND STATE
48 COMPARISONS;

49 (II) THE CHARACTERISTICS OF REGISTRANTS AS DETERMINED FROM THE PBSC
50 REGISTRY INFORMATION;

51 (III) THE ANNUAL DOLLAR AMOUNT OF VOLUNTARY CONTRIBUTIONS RECEIVED BY
52 THE CONTRACTOR FOR THE PURPOSES OF MAINTAINING THE PBSC REGISTRY AND/OR
53 EDUCATIONAL AND PROMOTIONAL CAMPAIGNS AND INITIATIVES;

54 (IV) A DESCRIPTION OF THE PROMOTIONAL CAMPAIGNS AND INITIATIVES IMPL-
55 MENTED DURING THE YEAR; AND

(V) ACCOUNTING STATEMENTS OF EXPENDITURES FOR THE PURPOSES OF MAINTAINING THE PBSC REGISTRY AND PROMOTIONAL CAMPAIGNS AND INITIATIVES.

4. (A) FOR THE PERIOD APRIL FIRST, TWO THOUSAND SIXTEEN THROUGH MARCH THIRTY-FIRST, TWO THOUSAND SEVENTEEN, PAYMENTS TO THE CONTRACTOR SHALL BE PAID BY THE DEPARTMENT.

(B) FOR THE PERIOD BEGINNING APRIL FIRST, TWO THOUSAND SEVENTEEN AND THEREAFTER, PAYMENTS TO THE CONTRACTOR SHALL BE PAID BY THE DEPARTMENT FROM FUNDS AVAILABLE FOR THESE PURPOSES, INCLUDING, BUT NOT LIMITED TO, THE FUNDS DEPOSITED INTO THE LIFE PASS IT ON TRUST FUND PURSUANT TO SECTION NINETY-FIVE-D OF THE STATE FINANCE LAW, AS ADDED BY CHAPTER FOUR HUNDRED FIFTEEN OF THE LAWS OF TWO THOUSAND THREE.

(C) IN ADDITION, THE CONTRACTOR MAY RECEIVE AND USE VOLUNTARY CONTRIBUTIONS.

5. (A) SUCH BONE MARROW AND PERIPHERAL BLOOD STEM CELL REGISTRATION OF CONSENT TO MAKE AN ANATOMICAL GIFT CAN BE MADE THROUGH: (I) INDICATION MADE ON THE APPLICATION OR RENEWAL FORM OF A DRIVER'S LICENSE, (II) INDICATION MADE ON A NON-DRIVER IDENTIFICATION CARD APPLICATION OR RENEWAL FORM, (III) INDICATION MADE ON A VOTER REGISTRATION FORM PURSUANT TO SUBDIVISION FIVE OF SECTION 5-210 OF THE ELECTION LAW, (IV) ENROLLMENT THROUGH THE PBSC REGISTRY WEBSITE, (V) PAPER ENROLLMENT SUBMITTED TO THE PBSC REGISTRY, OR (VI) THROUGH ANY OTHER METHOD IDENTIFIED BY THE COMMISSIONER.

(B)(I) WHERE REQUIRED BY LAW FOR REGISTRATION FORMS DESCRIBED IN SUBPARAGRAPHS (I) AND (II) OF PARAGRAPH (A) OF THIS SUBDIVISION, THE COMMISSIONER OF MOTOR VEHICLES SHALL ENSURE THAT SPACE IS PROVIDED ON ANY REGISTRATION FORM SO THAT THE APPLICANT SHALL REGISTER OR DECLINE REGISTRATION IN THE PBSC REGISTRY FOR ORGAN, EYE AND TISSUE DONATIONS UNDER THIS SECTION AND THAT THE FOLLOWING IS STATED ON THE FORM IN CLEAR AND CONSPICUOUS TYPE:

"YOU MUST FILL OUT THE FOLLOWING SECTION: WOULD YOU LIKE TO BE ADDED TO THE NEW YORK STATE BONE MARROW AND PERIPHERAL BLOOD STEM CELL DONATION REGISTRY? CHECK BOX FOR 'YES' OR 'SKIP THIS QUESTION'."

(II) THE COMMISSIONER SHALL NOT MAINTAIN RECORDS OF ANY PERSON WHO CHECKS "SKIP THIS QUESTION". FAILURE TO CHECK A BOX SHALL NOT IMPAIR THE VALIDITY OF AN APPLICATION, AND FAILURE TO CHECK "YES" OR CHECKING "SKIP THIS QUESTION" SHALL NOT BE CONSTRUED TO IMPLY A WISH NOT TO DONATE. IN THE CASE OF AN APPLICANT UNDER EIGHTEEN YEARS OF AGE, CHECKING "YES" SHALL NOT CONSTITUTE CONSENT TO MAKE AN ANATOMICAL GIFT OR REGISTRATION IN THE PBSC REGISTRY. WHERE AN APPLICANT HAS PREVIOUSLY CONSENTED TO MAKE A BONE MARROW AND PERIPHERAL BLOOD STEM CELLS GIFT OR REGISTERED IN THE PBSC REGISTRY, CHECKING "SKIP THIS QUESTION" OR FAILING TO CHECK A BOX SHALL NOT IMPAIR THAT CONSENT OR REGISTRATION.

(C) ENROLLMENT OR AMENDMENT OR REVOCATION THROUGH THE PBSC REGISTRY WEBSITE THROUGH ANY OF THE MEANS LISTED IN THIS SUBDIVISION MAY BE SIGNED BY ELECTRONIC SIGNATURE, IN ACCORDANCE WITH THE PROVISIONS OF ARTICLE THREE OF THE STATE TECHNOLOGY LAW, SUPPORTED BY THE USE OF SUITABLE MECHANISMS INCLUDING UNIQUE IDENTIFIERS TO PROVIDE CONFIDENCE IN THE IDENTITY OF THE PERSON PROVIDING THE ELECTRONIC SIGNATURE. THE REGISTRATION SHALL TAKE EFFECT UPON THE PROVISION OF WRITTEN OR ELECTRONIC NOTICE OF THE REGISTRATION TO THE INDIVIDUAL ENROLLING IN THE PBSC REGISTRY.

(D) AMENDMENTS OR REVOCATIONS FROM THE PBSC REGISTRY SHALL BE MADE BY THE FOLLOWING, SUBJECT TO THE REQUIREMENTS OF THE COMMISSIONER:

(I) REGISTRANTS SUBMITTING AN AMENDMENT OR REVOCATION IN WRITING TO THE PBSC REGISTRY; OR

1 (II) REGISTRANTS SUBMITTING AN AMENDMENT OR REVOCATION ELECTRONICALLY
2 THROUGH THE PBSC REGISTRY WEBSITE.

3 (E) REMOVAL FROM THE PBSC REGISTRY SHALL NOT BE DEEMED A REFUSAL OF
4 ANY OTHER OR FUTURE BONE MARROW AND PERIPHERAL BLOOD STEM CELLS GIFT OR
5 ANATOMICAL GIFT.

6 (F) THE PBSC REGISTRY SHALL PROVIDE AN ENROLLED INDIVIDUAL THE OPPOR-
7 TUNITY TO SPECIFY WHETHER HE OR SHE WISHES TO DONATE BONE MARROW,
8 PERIPHERAL BLOOD STEM CELLS OR BOTH AND IF THE DONATION MAY BE USED FOR
9 TRANSPLANTATION, RESEARCH, OR BOTH.

10 6. (A) THE PBSC REGISTRY SHALL BE MAINTAINED IN A MANNER THAT ALLOWS
11 IMMEDIATE ACCESS TO BONE MARROW AND PERIPHERAL BLOOD STEM CELL DONATION
12 RECORDS TWENTY-FOUR HOURS A DAY, SEVEN DAYS A WEEK TO THE CONTRACTOR,
13 THE DEPARTMENT, FEDERALLY DESIGNATED BONE MARROW AND PERIPHERAL BLOOD
14 STEM CELLS PROCUREMENT ORGANIZATIONS IN APPROPRIATE CASES AND SUCH OTHER
15 ENTITIES WHICH MAY BE APPROVED BY THE DEPARTMENT FOR ACCESS. ACCESS
16 SHALL BE AVAILABLE TO REGISTRANTS TO CONFIRM THE ACCURACY AND VALIDITY
17 OF THEIR REGISTRATION AND TO AMEND OR REVOKE THEIR REGISTRATION, SUBJECT
18 TO REASONABLE PROCEDURES TO VERIFY IDENTITY.

19 (B) ACCESS TO THE PBSC REGISTRY SHALL HAVE SECURITY MEASURES SET FORTH
20 IN THE CONTRACT TO PROTECT THE INTEGRITY OF THE IDENTIFIABLE DATA IN THE
21 PBSC REGISTRY, WHICH MAY ONLY BE ACCESSED BY THE PARTIES DESCRIBED IN
22 PARAGRAPH (A) OF THIS SUBDIVISION AND ONLY FOR THE PURPOSES OF DETERMIN-
23 ING DONOR STATUS OR IDENTIFYING POTENTIAL BONE MARROW OR PERIPHERAL
24 BLOOD STEM CELL DONORS, BY THE DEPARTMENT FOR ANY PURPOSE, BY THE
25 CONTRACTOR ONLY FOR PURPOSES OF QUALITY ASSESSMENT AND IMPROVEMENT,
26 TECHNICAL SUPPORT AND DONOR SERVICES, OR BY INDIVIDUAL REGISTRANTS FOR
27 THE PURPOSES OF CONFIRMING THE ACCURACY AND VALIDITY OF THEIR REGISTRA-
28 TION OR MAKING, AMENDING OR REVOKING THEIR REGISTRATION.

29 (C) DE-IDENTIFIED INFORMATION MAY BE ACCESSED BY THE ENTITIES LISTED
30 IN PARAGRAPH (A) OF THIS SUBDIVISION OR THEIR DESIGNEES FOR PURPOSES OF
31 ANALYSIS, PROMOTION, EDUCATION, QUALITY IMPROVEMENT AND TECHNICAL
32 SUPPORT FOR THE PBSC REGISTRY. THE INFORMATION CONTAINED IN THE REGIS-
33 TRY SHALL NOT BE RELEASED TO ANY PERSON EXCEPT AS EXPRESSLY AUTHORIZED
34 BY THIS SECTION, SOLELY FOR THE PURPOSES SO AUTHORIZED.

35 7. THE REGISTRATION OF BONE MARROW OR PERIPHERAL BLOOD STEM CELL
36 DONORS SHALL BE FOR THE PURPOSE OF IDENTIFYING THE DONORS AND TRANS-
37 FERRING THEIR REGISTRATION INFORMATION TO A FEDERALLY-REGULATED BONE
38 MARROW OR PERIPHERAL BLOOD STEM CELL PROCUREMENT AGENCY.

39 8. THE COMMISSIONER IS AUTHORIZED TO PROMULGATE RULES AND REGULATIONS
40 NECESSARY TO IMPLEMENT THE PROVISIONS OF THIS SECTION.

41 9. AN INTERAGENCY WORK GROUP, COMPOSED OF THE COMMISSIONER, THE
42 COMMISSIONER OF THE DEPARTMENT OF MOTOR VEHICLES, A CHAIR OF THE BOARD
43 OF ELECTIONS, OR THEIR DESIGNEES, AND SUCH OTHER INDIVIDUALS AS MAY BE
44 DESIGNATED BY THE COMMISSIONER, SHALL BE ESTABLISHED TO MEET WITH THE
45 CONTRACTOR ANNUALLY AND AS NEEDED TO REVIEW THE STATUS OF THE PBSC
46 REGISTRY, TO EXAMINE THE STEPS THAT MIGHT BE TAKEN BY STATE AGENCIES TO
47 ENHANCE ITS PERFORMANCE AND TO MAKE RECOMMENDATIONS TO THE CONTRACTOR.

48 S 5. Subdivision 3 of section 95-d of the state finance law, as
49 amended by section 29 of part A of chapter 60 of the laws of 2014, is
50 amended to read as follows:

51 3. Monies of the fund shall be expended only for organ transplant
52 research and education projects approved by the commissioner of health,
53 or to provide grants to not-for-profit corporations in this state which
54 are incorporated for the purpose of increasing and promoting organ and
55 tissue donation awareness AND BONE MARROW AND PERIPHERAL BLOOD STEM CELL
56 DONATION AWARENESS provided, however, THAT: (A) beginning April first,

1 two thousand fifteen, any revenues received or any monies appropriated,
2 credited or transferred to the fund on and after May first, two thousand
3 fourteen may also be expended to support the maintenance and operation
4 of the donate life registry in accordance with the provisions of section
5 forty-three hundred ten of the public health law; AND (B) BEGINNING
6 APRIL FIRST, TWO THOUSAND SIXTEEN, ANY REVENUES RECEIVED OR ANY MONIES
7 APPROPRIATED, CREDITED OR TRANSFERRED TO THE FUND ON AND AFTER MAY
8 FIRST, TWO THOUSAND FIFTEEN MAY ALSO BE EXPENDED TO SUPPORT THE MAINTENANCE
9 AND OPERATION OF THE THE PBSC REGISTRY IN ACCORDANCE WITH THE
10 PROVISIONS OF SECTION FORTY-THREE HUNDRED ELEVEN OF THE PUBLIC HEALTH
11 LAW.

12 S 6. Paragraph (k) of subdivision 5 of section 5-210 of the election
13 law is amended by adding a new subparagraph (xiii) to read as follows:

14 (XIII) A SPACE FOR THE APPLICANT TO REGISTER IN THE NEW YORK STATE
15 BONE MARROW AND PERIPHERAL BLOOD STEM CELL DONATION REGISTRY ESTABLISHED
16 PURSUANT TO SECTION FORTY-THREE HUNDRED ELEVEN OF THE PUBLIC HEALTH LAW.

17 S 7. This act shall take effect on the ninetieth day after it shall
18 have become a law.