S T A T E O F N E W Y O R K

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:

Section 1. This act shall be known and may be cited as "Jaden's law".

S 2. Subdivision 1 of section 207 of the public health law is amended by adding a new paragraph (l) to read as follows:

(L) BONE MARROW AND PERIPHERAL BLOOD STEM CELL DONATION.

S 3. The public health law is amended by adding a new section 4369 to read as follows:

S 4369. BONE MARROW AND PERIPHERAL BLOOD STEM CELL INFORMATION. 1. A PHYSICIAN, AS EARLY AS PRACTICABLE IN THE PHYSICIAN'S THERAPEUTIC RELATIONSHIP WITH A PATIENT, AND UNLESS THE PHYSICIAN REASONABLY BELIEVES THAT BONE MARROW OR PBSC DONATION WOULD THREATEN THE HEALTH OF THE PATIENT, MAY PROVIDE A COPY OF THE BROCHURE PREPARED BY THE COMMISSIONER TO EVERY PATIENT:

(A) WHO IS KNOWN BY THE PHYSICIAN TO BE AT LEAST EIGHTEEN YEARS OF AGE BUT NO OLDER THAN SIXTY YEARS OF AGE; AND

(B) WHO THE PHYSICIAN ANTICIPATES WILL BE ADMITTED TO A HOSPITAL FOR AN ELECTIVE ORTHOPEDIC PROCEDURE OR TREATMENT OR OTHERWISE BELIEVES IS AN APPROPRIATE CANDIDATE FOR BONE MARROW OR PBSC DONATION; OR FOR WHOM 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.

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

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

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

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

S 4311. NEW YORK STATE BONE MARROW AND PERIPHERAL BLOOD STEM CELL DONATION REGISTRY. 1. THE DEPARTMENT SHALL ESTABLISH A BONE MARROW AND PERIPHERAL BLOOD STEM CELL (PBSC) DONATION REGISTRY, TO BE KNOWN AS THE "PBSC REGISTRY", WHICH SHALL PROVIDE A MEANS TO MAKE AND REGISTER A GIFT OF BONE MARROW AND PERIPHERAL BLOOD STEM CELLS TO TAKE PLACE PURSUANT TO THE PROVISIONS OF THIS ARTICLE. THE PBSC REGISTRY SHALL CONTAIN A LISTING OF ALL DONORS WHO HAVE DECLARED THEIR CONSENT TO MAKE SUCH ANATOMICAL GIFTS.

2. THE COMMISSIONER MAY ENTER INTO A MULTI-YEAR CONTRACT FOR THE OPERATION AND PROMOTION OF THE PBSC REGISTRY, SUBJECT TO SUCH TERMS AND CONDITIONS AS MAY BE CONTAINED WITHIN SUCH CONTRACT WITH A NOT-FOR-PROFIT ORGANIZATION THAT HAS EXPERIENCE WORKING WITH DONATION COMMUNITIES THROUGHOUT THE STATE. THE CONTRACTOR MAY SUBCONTRACT AS NEEDED FOR THE EFFECTIVE PERFORMANCE OF THE CONTRACT. ALL SUCH SUBCONTRACTORS AND THE TERMS OF SUCH SUBCONTRACTS SHALL BE SUBJECT TO APPROVAL BY THE COMMISSIONER. ANY APPLICABLE STATE AGENCY, INCLUDING, BUT NOT LIMITED TO, THE DEPARTMENT, THE DEPARTMENT OF MOTOR VEHICLES AND THE BOARD OF ELECTIONS, SHALL COOPERATE IN THE COLLECTION AND TRANSFER OF REGISTRANT DATA TO THE PBSC REGISTRY.

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

(A) THE DEVELOPMENT, IMPLEMENTATION AND MAINTENANCE OF THE PBSC REGISTRY THAT INCLUDES ONLINE, MAILED AND OTHER FORMS OF BONE MARROW AND PERIPHERAL BLOOD STEM CELL DONOR REGISTRATION, VERIFICATION, AMENDMENT AND REVOCATION;

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

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

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

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

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

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

(IV) A DESCRIPTION OF THE PROMOTIONAL CAMPAIGNS AND INITIATIVES IMPLEMENTED 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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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