

5046

2013-2014 Regular Sessions

I N   S E N A T E

May 7, 2013

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Introduced by Sen. HANNON -- read twice and ordered printed, and when printed to be committed to the Committee on Health

AN ACT to amend the public health law and the state finance law, in relation to organ, eye and tissue donation

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

1     Section 1. Section 4310 of the public health law, as amended by chap-  
2     ter 639 of the laws of 2006, the section heading as separately amended  
3     by chapter 640 of the laws of 2006, subdivisions 1 and 3 as amended by  
4     chapter 158 of the laws of 2012 and subdivision 2 as separately amended  
5     by chapters 158 and 465 of the laws of 2012, is amended to read as  
6     follows:

7     S 4310. New York state donate life registry for organ, EYE and tissue  
8     donations. 1. LEGISLATIVE FINDINGS AND INTENT. THE LEGISLATURE FINDS  
9     THAT THERE IS A NEED TO INCREASE THE NUMBER OF ORGAN, EYE AND TISSUE  
10    DONORS TO SAVE AND IMPROVE LIVES IN THIS STATE. ONLY TWENTY PERCENT OF  
11    ELIGIBLE NEW YORKERS ARE CURRENTLY IN THE DONATE LIFE REGISTRY TO MAKE  
12    AN ANATOMICAL GIFT UPON THEIR DEATH, THE THIRD LOWEST DONOR DESIGNATION  
13    SHARE IN THE NATION, WHILE THE STATE OF NEW YORK HAS THE THIRD HIGHEST  
14    NEED FOR ORGAN DONORS IN THE UNITED STATES AND ONE OF THE LONGEST AVER-  
15    AGE WAITING TIMES FOR KIDNEY TRANSPLANTS. A STATEWIDE ORGAN, EYE AND  
16    TISSUE DONOR REGISTRY COUPLED WITH AN ENHANCED PROGRAM OF PROMOTION OF  
17    SUCH REGISTRY, WILL LEAD TO AN INCREASE IN THE NUMBER OF ORGAN, EYE AND  
18    TISSUE DONORS REGISTERED IN THIS STATE, THEREBY AFFORDING MORE PERSONS  
19    WHO ARE AWAITING ORGAN, EYE OR TISSUE TRANSPLANTS THE OPPORTUNITY FOR A  
20    FULL AND PRODUCTIVE LIFE.

21    2. The department shall establish an organ, EYE, and tissue donor  
22    registry, which shall be called and be referred to as the "donate life  
23    registry", WHICH SHALL PROVIDE A MEANS TO MAKE AND REGISTER A GIFT OF  
24    ORGANS, EYES AND TISSUES TO TAKE PLACE AFTER DEATH PURSUANT TO SECTION  
25    FORTY-THREE HUNDRED ONE AND OTHER APPLICABLE PROVISIONS OF THIS ARTICLE.

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

LBD10414-01-3

1 [Such registry shall contain a listing of all donors who have declared  
2 their consent to make an anatomical gift.

3 2.] THE DEPARTMENT SHALL ENTER INTO A CONTRACT FOR THE OPERATION AND  
4 PROMOTION OF SUCH REGISTRY WITH A NOT-FOR-PROFIT STATEWIDE ORGANIZATION  
5 THAT HAS EXPERIENCE WORKING WITH ORGAN, EYE AND TISSUE PROCUREMENT  
6 ORGANIZATIONS, HAS EXPERTISE IN CONDUCTING ORGAN, EYE AND TISSUE DONOR  
7 PROMOTIONAL CAMPAIGNS, AND IS AFFILIATED WITH THE ORGAN, EYE AND TISSUE  
8 DONATION COMMUNITY THROUGHOUT THE STATE. THE CONTRACTOR MAY SUBCONTRACT  
9 AS NEEDED FOR THE EFFECTIVE PERFORMANCE OF THE CONTRACT. ALL SUCH  
10 SUBCONTRACTORS SHALL BE SUBJECT TO APPROVAL BY THE DEPARTMENT. THE  
11 DEPARTMENT, THE DEPARTMENT OF MOTOR VEHICLES, THE STATE BOARD OF  
12 ELECTIONS AND ANY OTHER APPLICABLE STATE AGENCY SHALL COOPERATE IN THE  
13 COLLECTION OF REGISTRANT DATA AND ENSURE SECURE TRANSFER OF THIS DATA TO  
14 THE CONTRACTOR.

15 3. THE DUTIES OF THE CONTRACTOR SHALL INCLUDE THE FOLLOWING:

16 (A) THE DEVELOPMENT, IMPLEMENTATION AND MAINTENANCE OF AN ORGAN, EYE  
17 AND TISSUE DONOR REGISTRY THAT MAY ALLOW FOR ONLINE, MAILED AND OTHER  
18 FORMS OF ORGAN, EYE AND TISSUE DONOR REGISTRATION, VERIFICATION, AMEND-  
19 MENT AND REVOCATION.

20 (I) THE REGISTRY SHALL BE MAINTAINED IN A MANNER THAT ALLOWS IMMEDIATE  
21 ACCESS TO ORGAN, EYE AND TISSUE DONATION RECORDS TWENTY-FOUR HOURS A  
22 DAY, SEVEN DAYS A WEEK TO THE CONTRACTOR, FEDERALLY DESIGNATED ORGAN  
23 PROCUREMENT ORGANIZATIONS, LICENSED EYE AND TISSUE BANKS, AND SUCH OTHER  
24 ENTITIES WHICH MAY BE APPROVED BY THE DEPARTMENT FOR ACCESS.

25 (II) ACCESS TO THE REGISTRY SHALL HAVE SECURITY MEASURES AS SET FORTH  
26 IN THE CONTRACT TO PROTECT THE INTEGRITY OF THE IDENTIFIABLE DATA IN THE  
27 REGISTRY, WHICH MAY ONLY BE ACCESSED BY THE PARTIES DESCRIBED IN SUBPAR-  
28 AGRAPH (I) OF THIS PARAGRAPH AND ONLY FOR THE PURPOSES OF DETERMINING  
29 DONOR STATUS AT OR NEAR THE TIME OF DEATH OF AN INDIVIDUAL, OR, BY THE  
30 CONTRACTOR ONLY FOR PURPOSES OF QUALITY ASSESSMENT AND IMPROVEMENT,  
31 TECHNICAL SUPPORT AND DONOR SERVICE.

32 (III) DE-IDENTIFIED INFORMATION MAY BE ACCESSED BY THE ENTITIES LISTED  
33 IN SUBPARAGRAPH (I) OF THIS PARAGRAPH OR THEIR DESIGNEES FOR PURPOSES OF  
34 ANALYSIS, PROMOTION, EDUCATION, QUALITY IMPROVEMENT AND TECHNICAL  
35 SUPPORT; AND

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

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

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

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

47 (IV) A DESCRIPTION OF THE PROMOTIONAL CAMPAIGNS AND INITIATIVES IMPE-  
48 MENTED DURING THE YEAR; AND

49 (V) ACCOUNTING STATEMENTS OF EXPENDITURES FOR THE PURPOSES OF MAIN-  
50 TAINING THE REGISTRY AND PROMOTIONAL CAMPAIGNS AND INITIATIVES.

51 4. PAYMENTS TO THE CONTRACTOR FOR THE OPERATION OF THE ORGAN, EYE AND  
52 TISSUE DONOR REGISTRY SHALL BE PAID BY THE DEPARTMENT FROM FUNDS AVAIL-  
53 ABLE FOR THESE PURPOSES, INCLUDING THE FUNDS DEPOSITED INTO THE LIFE  
54 PASS IT ON TRUST FUND PURSUANT TO SECTION NINETY-FIVE-D OF THE STATE  
55 FINANCE LAW, AS ADDED BY CHAPTER FOUR HUNDRED FIFTEEN OF THE LAWS OF TWO  
56 THOUSAND THREE, WHICH ARE DESIGNATED FOR MAINTAINING AND OPERATING THE

ORGAN, EYE AND TISSUE DONOR REGISTRY AND PROMOTION OF THE REGISTRY, AS DEEMED APPROPRIATE BY THE COMMISSIONER. IN ADDITION, THE CONTRACTOR MAY RECEIVE AND USE VOLUNTARY CONTRIBUTIONS.

5. (A) Such ORGAN, EYE AND TISSUE registration [of consent to make an anatomical gift] can be made through [(a)]: (I) indication made on the application or renewal form of a DRIVER'S license, [(b)] (II) indication made on a non-driver identification card application or renewal form, [(c)] (III) enrolling in the registry website maintained by the department, [which may include using an electronic signature subject to article three of the state technology law, (d)] (IV) indication made on a voter registration form pursuant to subdivision five of section 5-210 of the election law, (V) ENROLLMENT THROUGH THE ORGAN, EYE AND TISSUE DONOR REGISTRY WEBSITE MAINTAINED BY THE CONTRACTOR, (VI) PAPER ENROLLMENT SUBMITTED TO THE CONTRACTOR, or [(e)] (VII) through any other method identified by the commissioner. Where required by law for consent forms described in [paragraphs (a) and (b)] SUBPARAGRAPHS (I) AND (II) of this [subdivision] PARAGRAPH, the commissioner shall ensure that space is provided on any consent form so that the applicant shall register or decline registration in the donate life 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 Donate Life Registry? Check box for 'yes' or 'skip this question'."

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 donate life registry. Where an applicant has previously consented to make an anatomical gift or registered in the donate life registry, checking "skip this question" or failing to check a box shall not impair that consent or registration. ENROLLMENT THROUGH THE ORGAN, EYE AND TISSUE DONOR REGISTRY WEBSITE MAINTAINED BY THE CONTRACTOR THROUGH ANY OF THE MEANS LISTED ABOVE MAY BE SIGNED BY ELECTRONIC SIGNATURE, IN ACCORDANCE WITH THE PROVISIONS OF ARTICLE THREE OF THE STATE TECHNOLOGY LAW, SUPPORTED BY ATTESTATION. The registration shall take effect [upon the provision of] IMMEDIATELY AND written or electronic notice of the registration SHALL BE PROVIDED to the [person] INDIVIDUAL enrolling in the registry.

[3. (a) Information contained in the registry shall be accessible to (i) federally designated organ procurement organizations, (ii) eye and tissue banks licensed by the department pursuant to article forty-three-B of this chapter, and (iii) any other entity formally approved by the commissioner.

(b) The information contained in the registry shall not be released to any person except as expressly authorized by this section solely for the purpose of identifying potential organ and tissue donors at or near the time of death.

4. If the department had an established registry prior to the effective date of this section, it shall be deemed to meet the requirements of this section.

5. The registry shall provide persons enrolled the opportunity to specify which organs and tissues they want to donate and if the donation

can be used for transplantation, research, or both.] (B) AMENDMENTS MAY BE MADE BY THE FOLLOWING:

(I) REGISTRANTS SUBMITTING AN AMENDMENT IN WRITING TO THE CONTRACTOR; OR

(II) REGISTRANTS SUBMITTING AN AMENDMENT ELECTRONICALLY THROUGH THE ORGAN, EYE AND TISSUE DONOR REGISTRY WEBSITE MAINTAINED BY THE CONTRACTOR.

(C) REMOVAL FROM THE ORGAN, EYE AND TISSUE DONOR REGISTRY SHALL BE ACCOMPLISHED BY PROVIDING NOTIFICATION TO THE CONTRACTOR. REMOVAL FROM THE REGISTRY SHALL NOT BE DEEMED A REFUSAL OF ANY OTHER OR FUTURE ANATOMICAL GIFT.

(D) THE REGISTRY SHALL PROVIDE INDIVIDUALS ENROLLED THE OPPORTUNITY TO SPECIFY WHICH ORGANS AND TISSUES THEY WANT TO DONATE AND IF THE DONATION MAY BE USED FOR TRANSPLANTATION, RESEARCH, OR BOTH.

6. [A person] AN INDIVIDUAL registered in the [organ and tissue] DONATE LIFE registry before [the effective date of this subdivision] JULY TWENTY-THIRD, TWO THOUSAND EIGHT shall be deemed to have expressed [intent to donate, until and unless he or she files an amendment to his or her registration or a new registration expressing] consent to donate.

7. [The commissioner shall contact each person registered before the effective date of this subdivision in the organ and tissue registry in writing to inform him or her that at the time he or she registered, the registry was that of intent and that the registry is now one of consent, to explain in clear and understandable terms the difference between intent and consent, and to provide opportunity for the person to change his or her registration to provide consent by amending his or her current registration or executing a new registration.

8.] The commissioner is authorized to promulgate rules and regulations necessary to implement the provisions of this section.

S 2. Subdivision 2 of section 4310 of the public health law, as amended by chapter 158 of the laws of 2012, is amended to read as follows:

[2.] 5. (A) Such ORGAN, EYE AND TISSUE registration [of consent to make an anatomical gift] can be made through [(a)]: (I) indication made on the application or renewal form of a DRIVER'S license, [(b)] (II) indication made on a non-driver identification card application or renewal form, [(c)] (III) enrolling in the registry website maintained by the department, [which may include using an electronic signature subject to article three of the state technology law, (d)] (IV) indication made on a voter registration form pursuant to subdivision five of section 5-210 of the election law, (V) ENROLLMENT THROUGH THE ORGAN, EYE AND TISSUE DONOR REGISTRY WEBSITE MAINTAINED BY THE CONTRACTOR, (VI) PAPER ENROLLMENT SUBMITTED TO THE CONTRACTOR, or [(e)] (VII) through any other method identified by the commissioner. WHERE REQUIRED BY LAW FOR CONSENT FORMS DESCRIBED IN SUBPARAGRAPHS (I) AND (II) OF THIS PARAGRAPH, THE COMMISSIONER SHALL ENSURE THAT SPACE IS PROVIDED ON ANY CONSENT FORM SO THAT THE APPLICANT SHALL REGISTER OR DECLINE REGISTRATION IN THE DONATE LIFE 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 DONATE LIFE REGISTRY? CHECK BOX FOR 'YES' OR 'SKIP THIS QUESTION'."

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

1 QUESTION" SHALL NOT BE CONSTRUED TO IMPLY A WISH NOT TO DONATE. IN THE  
2 CASE OF AN APPLICANT UNDER EIGHTEEN YEARS OF AGE, CHECKING "YES" SHALL  
3 NOT CONSTITUTE CONSENT TO MAKE AN ANATOMICAL GIFT OR REGISTRATION IN THE  
4 DONATE LIFE REGISTRY. WHERE AN APPLICANT HAS PREVIOUSLY CONSENTED TO  
5 MAKE AN ANATOMICAL GIFT OR REGISTERED IN THE DONATE LIFE REGISTRY,  
6 CHECKING "SKIP THIS QUESTION" OR FAILING TO CHECK A BOX SHALL NOT IMPAIR  
7 THAT CONSENT OR REGISTRATION. ENROLLMENT THROUGH THE ORGAN, EYE AND  
8 TISSUE DONOR REGISTRY WEBSITE MAINTAINED BY THE CONTRACTOR THROUGH ANY  
9 OF THE MEANS LISTED ABOVE MAY BE SIGNED BY ELECTRONIC SIGNATURE, IN  
10 ACCORDANCE WITH THE PROVISIONS OF ARTICLE THREE OF THE STATE TECHNOLOGY  
11 LAW, SUPPORTED BY ATTESTATION. The registration shall take effect [upon  
12 the provision of] IMMEDIATELY AND written or electronic notice of the  
13 registration SHALL BE PROVIDED to the [person] INDIVIDUAL enrolling in  
14 the registry.

15 (B) AMENDMENTS CAN BE MADE BY THE FOLLOWING:

16 (I) REGISTRANTS SUBMITTING AN AMENDMENT IN WRITING TO THE CONTRACTOR;  
17 OR

18 (II) REGISTRANTS SUBMITTING AN AMENDMENT ELECTRONICALLY THROUGH THE  
19 ORGAN, EYE AND TISSUE DONOR REGISTRY WEBSITE MAINTAINED BY THE CONTRAC-  
20 TOR.

21 (C) REMOVAL FROM THE ORGAN, EYE AND TISSUE DONOR REGISTRY SHALL BE  
22 ACCOMPLISHED BY PROVIDING NOTIFICATION TO THE CONTRACTOR. REMOVAL FROM  
23 THE REGISTRY SHALL NOT BE DEEMED A REFUSAL OF ANY OTHER OR FUTURE  
24 ANATOMICAL GIFT.

25 (D) THE REGISTRY SHALL PROVIDE INDIVIDUALS ENROLLED THE OPPORTUNITY TO  
26 SPECIFY WHICH ORGANS AND TISSUES THEY WANT TO DONATE AND IF THE DONATION  
27 MAY BE USED FOR TRANSPLANTATION, RESEARCH, OR BOTH.

28 S 3. Subdivision 3 of section 95-d of the state finance law, as added  
29 by chapter 415 of the laws of 2003, is amended to read as follows:

30 3. Monies of the fund shall be expended [only for organ transplant  
31 research and education projects approved by the commissioner of health,  
32 or to provide grants to not-for-profit corporations in this state which  
33 are incorporated for the purpose of increasing and promoting organ and  
34 tissue donation awareness] TO SUPPORT TO MAINTENANCE AND OPERATION OF  
35 THE DONATE LIFE REGISTRY, IN ACCORDANCE WITH THE PROVISIONS OF SECTION  
36 FORTY-THREE HUNDRED TEN OF THE PUBLIC HEALTH LAW.

37 S 4. This act shall take effect on the sixtieth day after it shall  
38 have become a law; provided that the amendments to subdivision 2 of  
39 section 4310 of the public health law, made by section one of this act  
40 shall take effect on the same date and in the same manner as chapter 465  
41 of the laws of 2012 take effect, and the amendments made thereto shall  
42 not affect the expiration and reversion of such subdivision and shall  
43 expire and be deemed repealed therewith, when upon such date section two  
44 of this act shall take effect.