

5046--A

2013-2014 Regular Sessions

I N   S E N A T E

May 7, 2013

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Introduced by Sens. HANNON, CARLUCCI, LARKIN -- read twice and ordered printed, and when printed to be committed to the Committee on Health -- reported favorably from said committee and committed to the Committee on Finance -- committee discharged, bill amended, ordered reprinted as amended and recommitted to said committee

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. Legislative findings and intent. It is the intent of the  
2     legislature to enable the New York State donate life registry for organ,  
3     eye and tissue donations to enroll a greater number of New Yorkers as  
4     donors through the authorization of a public-private partnership that  
5     will foster innovative and cost-effective approaches toward enrollment  
6     of donors and that will remove unnecessary barriers to enrollment.  
7     S 2. Section 4310 of the public health law, as amended by chapter 639  
8     of the laws of 2006, the section heading as separately amended by chapter  
9     640 of the laws of 2006, subdivisions 1 and 3 as amended by chapter  
10    158 of the laws of 2012 and subdivision 2 as separately amended by chapters  
11    158 and 465 of the laws of 2012, is amended to read as follows:  
12    S 4310. New York state donate life registry for organ, EYE and tissue  
13    donations. 1. The department shall establish an organ, EYE, and tissue  
14    donor registry, which shall be called and be referred to as the "donate  
15    life registry", WHICH SHALL PROVIDE A MEANS TO MAKE AND REGISTER A GIFT  
16    OF ORGANS, EYES AND TISSUES TO TAKE PLACE AFTER DEATH PURSUANT TO  
17    SECTION FORTY-THREE HUNDRED ONE AND OTHER APPLICABLE PROVISIONS OF THIS  
18    ARTICLE. [Such registry shall contain a listing of all donors who have  
19    declared their consent to make an anatomical gift.]  
20    2. THE COMMISSIONER MAY ENTER INTO A CONTRACT FOR THE OPERATION AND  
21    PROMOTION OF SUCH REGISTRY SUBJECT TO SUCH TERMS AND CONDITIONS AS MAY  
22    BE CONTAINED WITHIN SUCH CONTRACT WITH A NOT-FOR-PROFIT STATEWIDE ORGAN-

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

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IZATION THAT HAS EXPERIENCE WORKING WITH ORGAN, EYE AND TISSUE PROCUREMENT ORGANIZATIONS, HAS EXPERTISE IN CONDUCTING ORGAN, EYE AND TISSUE DONOR PROMOTIONAL CAMPAIGNS, AND IS AFFILIATED WITH THE ORGAN, EYE AND TISSUE DONATION COMMUNITY THROUGHOUT THE STATE. THE CONTRACTOR MAY SUBCONTRACT AS NEEDED FOR THE EFFECTIVE PERFORMANCE OF THE CONTRACT. ALL SUCH SUBCONTRACTORS SHALL BE SUBJECT TO APPROVAL BY THE COMMISSIONER. THE DEPARTMENT, THE DEPARTMENT OF MOTOR VEHICLES, THE STATE BOARD OF ELECTIONS AND ANY OTHER APPLICABLE STATE AGENCY SHALL COOPERATE IN THE COLLECTION AND TRANSFER OF REGISTRANT DATA TO THE CONTRACTOR.

3. THE DUTIES OF THE CONTRACTOR MAY INCLUDE THE FOLLOWING:

(A) THE DEVELOPMENT, IMPLEMENTATION AND MAINTENANCE OF AN ORGAN, EYE AND TISSUE DONOR REGISTRY THAT MAY ALLOW FOR ONLINE, MAILED AND OTHER FORMS OF ORGAN, EYE AND TISSUE DONOR REGISTRATION, VERIFICATION, AMENDMENT AND REVOCATION.

(I) THE REGISTRY SHALL BE MAINTAINED IN A MANNER THAT ALLOWS IMMEDIATE ACCESS TO ORGAN, EYE AND TISSUE DONATION RECORDS TWENTY-FOUR HOURS A DAY, SEVEN DAYS A WEEK TO THE CONTRACTOR, FEDERALLY DESIGNATED ORGAN PROCUREMENT ORGANIZATIONS, LICENSED EYE AND TISSUE BANKS, AND SUCH OTHER ENTITIES WHICH MAY BE APPROVED BY THE DEPARTMENT FOR ACCESS. ACCESS SHALL ALSO BE AVAILABLE, TO THE EXTENT PRACTICABLE, TO REGISTRANTS TO CONFIRM THE ACCURACY AND VALIDITY OF THEIR REGISTRATION AND TO AMEND OR REVOKE THEIR REGISTRATION, SUBJECT TO REASONABLE PROCEDURES TO VERIFY THEIR IDENTITY.

(II) ACCESS TO THE REGISTRY SHALL HAVE SECURITY MEASURES AS SET FORTH IN THE CONTRACT TO PROTECT THE INTEGRITY OF THE IDENTIFIABLE DATA IN THE REGISTRY, WHICH MAY ONLY BE ACCESSED BY THE PARTIES DESCRIBED IN SUBPARAGRAPH (I) OF THIS PARAGRAPH AND ONLY FOR THE PURPOSES OF DETERMINING DONOR STATUS AT OR NEAR THE TIME OF DEATH OF AN INDIVIDUAL, BY THE CONTRACTOR ONLY FOR PURPOSES OF QUALITY ASSESSMENT AND IMPROVEMENT, TECHNICAL SUPPORT AND DONOR SERVICE, OR BY INDIVIDUAL REGISTRANTS FOR THE PURPOSES OF CONFIRMING THE ACCURACY AND VALIDITY OF THEIR REGISTRATION OR MAKING, AMENDING OR REVOKING THEIR REGISTRATION.

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

(B) PREPARATION AND SUBMISSION OF A PLAN TO ENCOURAGE ORGAN DONATION THROUGH EDUCATION AND MARKETING EFFORTS AND OTHER RECOMMENDATIONS THAT WOULD STREAMLINE AND ENHANCE THE COST-EFFECTIVE OPERATION OF THE REGISTRY; AND

(C) 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 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 REGISTRY INFORMATION;

(III) THE ANNUAL DOLLAR AMOUNT OF VOLUNTARY CONTRIBUTIONS RECEIVED BY THE CONTRACTOR FOR THE PURPOSES OF MAINTAINING THE 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 REGISTRY AND PROMOTIONAL CAMPAIGNS AND INITIATIVES.

1 4. PAYMENTS TO THE CONTRACTOR FOR THE OPERATION OF THE ORGAN, EYE AND  
2 TISSUE DONOR REGISTRY SHALL BE PAID BY THE DEPARTMENT FROM FUNDS AVAIL-  
3 ABLE FOR THESE PURPOSES, INCLUDING THE FUNDS DEPOSITED INTO THE LIFE  
4 PASS IT ON TRUST FUND PURSUANT TO SECTION NINETY-FIVE-D OF THE STATE  
5 FINANCE LAW, AS ADDED BY CHAPTER FOUR HUNDRED FIFTEEN OF THE LAWS OF TWO  
6 THOUSAND THREE, WHICH ARE DESIGNATED FOR MAINTAINING AND OPERATING THE  
7 ORGAN, EYE AND TISSUE DONOR REGISTRY AND PROMOTION OF THE REGISTRY, AS  
8 DEEMED APPROPRIATE BY THE COMMISSIONER. IN ADDITION, THE CONTRACTOR MAY  
9 RECEIVE AND USE VOLUNTARY CONTRIBUTIONS.

10 5. (A) Such ORGAN, EYE AND TISSUE registration [of consent to make an  
11 anatomical gift] can be made through [(a)]: (I) indication made on the  
12 application or renewal form of a DRIVER'S license, [(b)] (II) indication  
13 made on a non-driver identification card application or renewal form,  
14 [(c) enrolling in the registry website maintained by the department,  
15 which may include using an electronic signature subject to article three  
16 of the state technology law, (d)] (III) indication made on a voter  
17 registration form pursuant to subdivision five of section 5-210 of the  
18 election law, (IV) ENROLLMENT THROUGH THE ORGAN, EYE AND TISSUE DONOR  
19 REGISTRY WEBSITE, (V) PAPER ENROLLMENT SUBMITTED TO THE REGISTRY, or  
20 [(e)] (VI) through any other method identified by the commissioner.  
21 Where required by law for consent forms described in [paragraphs (a) and  
22 (b)] SUBPARAGRAPHS (I) AND (II) of this [subdivision] PARAGRAPH, the  
23 commissioner shall ensure that space is provided on any consent form so  
24 that the applicant shall register or decline registration in the donate  
25 life registry for organ, EYE and tissue donations under this section and  
26 that the following is stated on the form in clear and conspicuous type:

27 "You must fill out the following section: Would you like to be added  
28 to the Donate Life Registry? Check box for 'yes' or 'skip this ques-  
29 tion'."

30 The commissioner shall not maintain records of any person who checks  
31 "skip this question". Failure to check a box shall not impair the valid-  
32 ity of an application, and failure to check "yes" or checking "skip this  
33 question" shall not be construed to imply a wish not to donate. In the  
34 case of an applicant under eighteen years of age, checking "yes" shall  
35 not constitute consent to make an anatomical gift or registration in the  
36 donate life registry. Where an applicant has previously consented to  
37 make an anatomical gift or registered in the donate life registry,  
38 checking "skip this question" or failing to check a box shall not impair  
39 that consent or registration. ENROLLMENT THROUGH THE ORGAN, EYE AND  
40 TISSUE DONOR REGISTRY WEBSITE THROUGH ANY OF THE MEANS LISTED ABOVE MAY  
41 BE SIGNED BY ELECTRONIC SIGNATURE, IN ACCORDANCE WITH THE PROVISIONS OF  
42 ARTICLE THREE OF THE STATE TECHNOLOGY LAW, SUPPORTED BY THE USE OF  
43 UNIQUE IDENTIFIERS THAT PROVIDE CONFIDENCE IN THE IDENTITY OF THE PERSON  
44 PROVIDING THE ELECTRONIC SIGNATURE. The registration shall take effect  
45 upon the provision of A written RECEIPT or electronic notice of the  
46 registration to the [person] INDIVIDUAL enrolling in the registry.

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

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

1 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.

2  
3  
4 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:

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

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

7  
8 (C) REMOVAL FROM THE ORGAN, EYE AND TISSUE DONOR REGISTRY SHALL BE ACCOMPLISHED BY PROVIDING NOTIFICATION TO THE REGISTRY. REMOVAL FROM THE REGISTRY SHALL NOT BE DEEMED A REFUSAL OF ANY OTHER OR FUTURE ANATOMICAL GIFT.

9  
10 (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.

11 6. [A person] AN INDIVIDUAL registered in the [organ and tissue] DONATE LIFE registry before the effective date of this subdivision 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.

12  
13 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.

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

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17 S 3. 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:

18 [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) 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)] (III) indication made on a voter registration form pursuant to subdivision five of section 5-210 of the election law, (IV) ENROLLMENT THROUGH THE ORGAN, EYE AND TISSUE DONOR REGISTRY WEBSITE, (V) PAPER ENROLLMENT SUBMITTED TO THE REGISTRY, or [(e)] (VI) through any other method identified by the commissioner. ENROLLMENT THROUGH THE ORGAN, EYE AND TISSUE DONOR REGISTRY WEBSITE 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 THE USE OF UNIQUE IDENTIFIERS THAT PROVIDE CONFIDENCE IN THE IDENTITY OF THE PERSON PROVIDING THE ELECTRONIC SIGNATURE. The registration shall take effect upon the provision of A written RECEIPT or electronic notice of the registration to the [person] INDIVIDUAL enrolling in the registry.

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

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

1 (II) REGISTRANTS SUBMITTING AN AMENDMENT ELECTRONICALLY THROUGH THE  
2 ORGAN, EYE AND TISSUE DONOR REGISTRY WEBSITE.

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

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

10 S 4. Subdivision 3 of section 95-d of the state finance law, as added  
11 by chapter 415 of the laws of 2003, is amended to read as follows:

12 3. Monies of the fund shall be expended [only for organ transplant  
13 research and education projects approved by the commissioner of health,  
14 or to provide grants to not-for-profit corporations in this state which  
15 are incorporated for the purpose of increasing and promoting organ and  
16 tissue donation awareness] TO SUPPORT THE MAINTENANCE AND OPERATION OF  
17 THE DONATE LIFE REGISTRY, IN ACCORDANCE WITH THE PROVISIONS OF SECTION  
18 FORTY-THREE HUNDRED TEN OF THE PUBLIC HEALTH LAW, PROVIDED, HOWEVER,  
19 THAT ANY REMAINING FUNDS, NOT NECESSARY FOR THESE PURPOSES, MAY BE  
20 EXPENDED FOR ORGAN TRANSPLANT RESEARCH AND EDUCATION PROJECTS.

21 S 5. This act shall take effect on the sixtieth day after it shall  
22 have become a law; provided that the amendments to subdivision 2 of  
23 section 4310 of the public health law, made by section two of this act  
24 shall take effect on the same date and in the same manner as chapter 465  
25 of the laws of 2012 take effect, and the amendments made thereto shall  
26 not affect the expiration and reversion of such subdivision and shall  
27 expire and be deemed repealed therewith, when upon such date section  
28 three of this act shall take effect.