

7518--A

2013-2014 Regular Sessions

I N A S S E M B L Y

May 23, 2013

Introduced by M. of A. GOTTFRIED, ORTIZ -- read once and referred to the Committee on Health -- reported and referred to the Committee on Codes -- 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 chap-
9 ter 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 chap-
11 ters 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-
23 IZATION THAT HAS EXPERIENCE WORKING WITH ORGAN, EYE AND TISSUE PROCURE-

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

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MENT 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.

4. PAYMENTS TO THE CONTRACTOR FOR THE OPERATION OF THE ORGAN, EYE AND TISSUE DONOR REGISTRY SHALL BE PAID BY THE DEPARTMENT FROM FUNDS AVAIL-

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

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

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

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

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

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

54 4. If the department had an established registry prior to the effec-
55 tive date of this section, it shall be deemed to meet the requirements
56 of this section.

1 5. The registry shall provide persons enrolled the opportunity to
2 specify which organs and tissues they want to donate and if the donation
3 can be used for transplantation, research, or both.] (B) AMENDMENTS MAY
4 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
7 ORGAN, EYE AND TISSUE DONOR REGISTRY WEBSITE.

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

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

15 6. [A person] AN INDIVIDUAL registered in the [organ and tissue]
16 DONATE LIFE registry before the effective date of this subdivision shall
17 be deemed to have expressed intent to donate, until and unless he or she
18 files an amendment to his or her registration or a new registration
19 expressing consent to donate.

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

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

30 S 3. Subdivision 2 of section 4310 of the public health law, as
31 amended by chapter 158 of the laws of 2012, is amended to read as
32 follows:

33 [2.] 5. (A) Such ORGAN, EYE AND TISSUE registration [of consent to
34 make an anatomical gift] can be made through [(a)]: (I) indication made
35 on the application or renewal form of a DRIVER'S license, [(b)] (II)
36 indication made on a non-driver identification card application or
37 renewal form, [(c) enrolling in the registry website maintained by the
38 department, which may include using an electronic signature subject to
39 article three of the state technology law, (d)] (III) indication made on
40 a voter registration form pursuant to subdivision five of section 5-210
41 of the election law, (IV) ENROLLMENT THROUGH THE ORGAN, EYE AND TISSUE
42 DONOR REGISTRY WEBSITE, (V) PAPER ENROLLMENT SUBMITTED TO THE REGISTRY,
43 or [(e)] (VI) through any other method identified by the commissioner.
44 ENROLLMENT THROUGH THE ORGAN, EYE AND TISSUE DONOR REGISTRY WEBSITE
45 THROUGH ANY OF THE MEANS LISTED ABOVE MAY BE SIGNED BY ELECTRONIC SIGNA-
46 TURE, IN ACCORDANCE WITH THE PROVISIONS OF ARTICLE THREE OF THE STATE
47 TECHNOLOGY LAW, SUPPORTED BY THE USE OF UNIQUE IDENTIFIERS THAT PROVIDE
48 CONFIDENCE IN THE IDENTITY OF THE PERSON PROVIDING THE ELECTRONIC SIGNA-
49 TURE. The registration shall take effect upon the provision of A written
50 RECEIPT or electronic notice of the registration to the [person] INDI-
51 VIDUAL enrolling in the registry.

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

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

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

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

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

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

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

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