

107TH CONGRESS
1ST SESSION

S. 788

To amend the Public Health Service Act to establish a National Organ and Tissue Donor Registry that works in conjunction with State organ and tissue donor registries, to create a public-private partnership to launch an aggressive outreach and education campaign about organ and tissue donation and the Registry, and for other purposes.

IN THE SENATE OF THE UNITED STATES

APRIL 26, 2001

Mr. SCHUMER introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

A BILL

To amend the Public Health Service Act to establish a National Organ and Tissue Donor Registry that works in conjunction with State organ and tissue donor registries, to create a public-private partnership to launch an aggressive outreach and education campaign about organ and tissue donation and the Registry, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Motor Donor Act”.

1 **SEC. 2. NATIONAL ORGAN AND TISSUE DONOR REGISTRY.**

2 Part H of title III of the Public Health Service Act
3 (42 U.S.C. 273 et seq.) is amended by inserting before
4 section 371 the following:

5 “Subpart 1—National Organ Donor Registry

6 **“SEC. 370. NATIONAL ORGAN DONOR REGISTRY.**

7 “(a) PURPOSES.—The purposes of this subpart are—

8 “(1) to establish procedures that will increase
9 the number of individuals who register their intent
10 to be organ or tissue donors and to support State
11 efforts to provide for donor designations through
12 State motor vehicle driver’s license application proc-
13 esses;

14 “(2) to make it possible for Federal and State
15 governments to enhance the information received by
16 individuals regarding organ or tissue donation;

17 “(3) to ensure that timely and accurate infor-
18 mation regarding an individual’s wishes regarding
19 organ and tissue donation is made available; and

20 “(4) to provide grants to States to establish
21 organ and tissue donor registries through State
22 motor vehicle driver’s license application processes
23 and linkages to the National Registry.

24 “(b) DEFINITIONS.—In this subpart:

25 “(1) MOTOR VEHICLE DRIVER’S LICENSE.—The
26 term ‘motor vehicle driver’s license’ means any per-

1 sonal identification document issued by a State
2 motor vehicle authority.

3 “(2) STATE.—The term ‘State’ means each of
4 the 50 States and the District of Columbia.

5 “(c) ESTABLISHMENT OF REGISTRY.—

6 “(1) IN GENERAL.—The Secretary shall estab-
7 lish and maintain a national organ and tissue donor
8 registry (referred to in this section as the ‘Reg-
9 istry’).

10 “(2) DATABASE.—The Registry shall consist of
11 a database of information listing individuals who
12 have expressed an intent to be organ or tissue do-
13 nors. The information for each individual shall in-
14 clude such individual’s name, address, date of birth,
15 sex, height, and eye color, and a Registry identifica-
16 tion number assigned by the Secretary.

17 “(d) COORDINATION WITH STATES AND ORGAN PRO-
18 CUREMENT ORGANIZATIONS.—

19 “(1) STATES.—

20 “(A) INITIAL 2-YEAR PERIOD.—The Sec-
21 retary, during the 2-year period after the date
22 of enactment of the Motor Donor Act, shall—

23 “(i) coordinate activities with States
24 that have organ and tissue donor registries

1 operated through a State agency to share
2 existing data; and

3 “(ii) provide links between the Reg-
4 istry and such State agencies on an ongo-
5 ing basis.

6 “(B) INITIAL 4-YEAR PERIOD.—The Sec-
7 retary, during the 4-year period after the date
8 of enactment of the Motor Donor Act, shall co-
9 ordinate activities with States to promote and
10 encourage the establishment of organ and tissue
11 donor registries through the motor vehicle driv-
12 er’s license process.

13 “(2) ORGAN PROCUREMENT ORGANIZATIONS.—
14 The Secretary shall provide to each organ procure-
15 ment organization within the United States a means
16 by which the organization may promptly access the
17 Registry 24-hours a day using a password assigned
18 to the organization by the Secretary. In order to ob-
19 tain such a password, each such procurement orga-
20 nization shall designate staff members within the or-
21 ganization to receive the password and to access the
22 Registry.

23 “(e) WEBSITE.—

24 “(1) IN GENERAL.—The Secretary, not later
25 than 3 years following the date of enactment of the

1 Motor Donor Act, shall disseminate to all United
2 States citizens who reside within the United States
3 and who filed a Federal income tax return with the
4 Internal Revenue Service during the prior year, a
5 pamphlet that contains information about organ and
6 tissue donations and that includes an address for a
7 website where individuals may elect to participate in
8 the Registry.

9 “(2) NOTIFICATION.—Within 4 months after an
10 individual elects to participate in the Registry
11 through the website, the Secretary shall notify such
12 individual concerning the individual’s participation
13 in the Registry.

14 “(f) LIMITATIONS.—

15 “(1) ORGAN ALLOCATION.—Participation in the
16 Registry shall not affect organ or tissue allocation.
17 Standard State and national practices that deter-
18 mine the appropriate procurement organization for
19 obtaining consent for an individual’s organ or tissue
20 donation shall continue to apply to such determina-
21 tions.

22 “(2) REGISTRY OF INTENT.—The Registry
23 shall be considered a registry only of an individual’s
24 intent to serve as an organ or tissue donor. Partici-
25 pation in the Registry shall not be deemed to be the

1 provision of legally binding consent for organ or tis-
 2 sue donation except as provided by State law.

3 “(3) REQUEST TO CANCEL PARTICIPATION.—

4 Individuals who elect to participate in the Registry
 5 shall have the right to cancel such participation at
 6 any time. The Secretary shall notify individuals who
 7 elect to participate in the Registry of their right to
 8 cancel such participation and the procedure for can-
 9 celing such participation. The Secretary shall
 10 promptly remove from the Registry information con-
 11 cerning any individual who cancels participation in
 12 the Registry.

13 “(g) GRANTS TO STATES.—

14 “(1) IN GENERAL.—The Secretary is authorized
 15 to award grants to States that have applications ap-
 16 proved under paragraph (2) to enable such States to
 17 plan and implement State registries associated with
 18 the motor vehicle driver’s license application process
 19 and to provide for linkages with the Registry.

20 “(2) APPLICATIONS.—

21 “(A) IN GENERAL.—Each State desiring a
 22 grant under this subsection shall submit an ap-
 23 plication to the Secretary at such time, in such
 24 manner, and containing such information as the
 25 Secretary may require.

1 “(B) STATE PROCEDURE.—Each applica-
2 tion submitted under subparagraph (A) shall
3 demonstrate how the State will establish proce-
4 dures to allow an individual to make a legally
5 binding gift regarding organ and tissue dona-
6 tion by application or by designation made si-
7 multaneously with an application for a motor
8 vehicle driver’s license.

9 “(C) ASSURANCES.—Each application sub-
10 mitted under subparagraph (A) shall contain
11 assurances that the State procedures described
12 in subparagraph (B) will comply with the fol-
13 lowing requirements:

14 “(i) LICENSE APPLICATION.—The
15 State procedures shall include a process
16 whereby each State motor vehicle driver’s
17 license application (including any renewal
18 application) that is submitted to the appro-
19 priate State motor vehicle authority under
20 State law provides the individual submit-
21 ting the application with the option of des-
22 ignating the individual’s intent to be an
23 organ and tissue donor.

24 “(ii) DONOR DESIGNATION.—The
25 State procedures shall provide that the ap-

1 plication described in clause (i) shall con-
2 tain the question, ‘Do you wish to have the
3 organ donor designation in the State reg-
4 istry?’ or, if the State agency process pro-
5 vides, ‘Do you wish to have the organ
6 donor designation on your driver’s li-
7 cense?’.

8 “(iii) AFFIRMATIVE RESPONSE.—The
9 State procedures shall provide that only
10 those individuals who answer affirmatively
11 to the question described in clause (ii)
12 shall have their organ donor preference
13 noted in the State registry or, if applicable,
14 on their motor vehicle driver’s license.

15 “(iv) FORWARDING OF INFORMA-
16 TION.—The State procedures shall provide
17 that the State shall forward to the Reg-
18 istry the names of those individuals who
19 answer affirmatively to the question de-
20 scribed in clause (ii), that such information
21 shall be forwarded not later than 100 days
22 after the date of designation, and that any
23 change in designation or change of address
24 information shall also be forwarded to the
25 Registry.

1 “(v) NEGATIVE RESPONSE.—The
2 State procedures shall provide that the
3 name of any individual who chooses not to
4 have the organ donor designation included
5 in the State registry or, if applicable, on
6 the individual’s driver’s license will not be
7 forwarded to the Registry.

8 “(vi) ACCESS BY ORGAN PROCURE-
9 MENT ORGANIZATION.—The State proce-
10 dures shall provide that the information re-
11 garding an individual who answers affirm-
12 atively to the question described in clause
13 (ii) shall be recorded in the individual’s
14 computer record with the appropriate
15 State agency. The State agency shall pro-
16 vide 24-hour a day access to such donor
17 information to organ procurement organi-
18 zations, and the organ procurement organi-
19 zations shall not be assessed a fee or other
20 charge for such access.

21 “(3) PRIORITY.—The Secretary shall give pri-
22 ority in awarding grants under this subsection to
23 States that submit applications demonstrating that
24 the State has collaborated with organ procurement
25 organizations serving the State.

1 “(4) LIMITATION.—No grant awarded under
2 this subsection to any one State shall exceed
3 \$300,000.

4 “(h) ADVISORY TASK FORCE.—

5 “(1) IN GENERAL.—There is established an ad-
6 visory task force on organ and tissue donation (re-
7 ferred to in this subsection as the ‘Task Force’).

8 “(2) MEMBERSHIP.—

9 “(A) MEMBERS.—

10 “(i) IN GENERAL.—The Task Force
11 shall consist of 5 members, who shall be
12 appointed by the Secretary.

13 “(ii) QUALIFICATIONS.—

14 “(I) IN GENERAL.—The Sec-
15 retary shall appoint members of the
16 Task Force based upon their experi-
17 ence with organ or tissue donations,
18 organ procurement, or organ trans-
19 plants.

20 “(II) SPECIAL EXPERIENCE.—At
21 least 1 member of the Task Force
22 shall be a physician with experience in
23 performing organ transplants, and at
24 least 1 member of the Task Force

1 shall have experience in organ pro-
2 curement.

3 “(B) TERM.—

4 “(i) IN GENERAL.—Except as pro-
5 vided in this subparagraph, each member
6 of the Task Force shall be appointed for a
7 term of 3 years. Members of the Task
8 Force may be reappointed.

9 “(ii) STAGGERED TERMS.—As so des-
10 ignated by the Secretary at the time of ap-
11 pointment, the terms of two of the initial
12 members shall expire at the end of 2 years.

13 “(C) VACANCIES.—Any vacancy in the
14 Task Force shall not affect the Task Force’s
15 powers but shall be filled in the same manner
16 as the original appointment.

17 “(3) FUNCTIONS.—

18 “(A) PARTNERSHIP.—The Task Force
19 shall offer to enter into a partnership with the
20 Coalition on Donation (a national membership
21 organization with the sole purpose of increasing
22 organ and tissue donations) to incorporate into
23 the Coalition’s national awareness campaign an
24 outreach and awareness campaign for the Reg-
25 istry.

1 “(B) REPORT.—Not later than 1 year
 2 after the date of enactment of the Motor Donor
 3 Act, the Task Force shall conduct a study con-
 4 cerning, and submit to the Secretary a report
 5 containing, recommendations for improving the
 6 Registry, increasing public awareness about
 7 organ and tissue donation, and improving the
 8 organ and tissue donation process.

9 “(4) ADMINISTRATION.—

10 “(A) PERSONNEL.—

11 “(i) TRAVEL EXPENSES.—The mem-
 12 bers of the Task Force shall not receive
 13 compensation for the performance of serv-
 14 ices for the Task Force, but shall be al-
 15 lowed travel expenses, including per diem
 16 in lieu of subsistence, at rates authorized
 17 for employees of agencies under subchapter
 18 I of chapter 57 of title 5, United States
 19 Code, while away from their homes or reg-
 20 ular places of business in the performance
 21 of services for the Task Force. Notwith-
 22 standing section 1342 of title 31, United
 23 States Code, the Secretary may accept the
 24 voluntary and uncompensated services of
 25 members of the Task Force.

1 “(ii) DETAIL OF GOVERNMENT EM-
 2 PLOYEES.—Any Federal Government em-
 3 ployee may be detailed to the Task Force
 4 without reimbursement, and such detail
 5 shall be without interruption or loss of civil
 6 service status or privilege.

7 “(B) ADMINISTRATIVE SUPPORT.—The
 8 Department of Health and Human Services
 9 shall provide necessary and appropriate admin-
 10 istrative support to the Task Force.

11 “(5) PERMANENT COMMITTEE.—Section 14 of
 12 the Federal Advisory Committee Act (5 U.S.C.
 13 App.) shall not apply to the Task Force.

14 “(i) AUTHORIZATION OF APPROPRIATIONS.—

15 “(1) IN GENERAL.—

16 “(A) REGISTRY AND GRANTS.—There is
 17 authorized to be appropriated to carry out this
 18 section, other than subsection (h)(3), such sums
 19 as may be necessary for each of fiscal years
 20 2002 through 2006.

21 “(B) AWARENESS CAMPAIGN.—There is
 22 authorized to be appropriated to carry out sub-
 23 section (h)(3), \$3,000,000 for each of fiscal
 24 years 2002 through 2006.

1 “(2) AVAILABILITY.—Any amounts appro-
 2 priated pursuant to paragraph (1) shall remain
 3 available until expended.

4 “Subpart 2—Organ Procurement”.

5 **SEC. 3. AMENDMENT OF INTERNAL REVENUE CODE.**

6 Section 6103(m) of the Internal Revenue Code of
 7 1986 (relating to disclosure of taxpayer identity informa-
 8 tion) is amended by adding at the end the following:

9 “(18) DISCLOSURE OF TAXPAYER IDENTIFICA-
 10 TION TO CARRY OUT ORGAN DONOR PROGRAM.—

11 “(A) IN GENERAL.—The Secretary may,
 12 upon written request from the Secretary of
 13 Health and Human Services, disclose to officers
 14 and employees of the Department of Health
 15 and Human Services the name and address of
 16 each individual filing a return of tax under sec-
 17 tion 6012 for the previous taxable year.

18 “(B) RESTRICTION ON USE OF DISCLOSED
 19 INFORMATION.—Return information disclosed
 20 under subparagraph (A) may be used by offi-
 21 cers and employees of the Department of
 22 Health and Human Services only for the pur-
 23 poses of, and to the extent necessary in, car-
 24 rying out the requirement to contact individuals
 25 regarding the national organ and tissue donor

1 registry under section 370(c) of the Public
2 Health Service Act.”.

3 **SEC. 4. CONFORMING AMENDMENTS.**

4 Subpart 2 of part H of title III of the Public Health
5 Service Act (as so designated) (42 U.S.C. 273 et seq.) is
6 amended in sections 374(a), 374(d), 375(1), and 378, by
7 striking “this part” each place it appears and inserting
8 “this subpart”.

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