

113<sup>TH</sup> CONGRESS  
2<sup>D</sup> SESSION

# H. R. 5218

To amend the Public Health Service Act to establish a National Organ and Tissue Donor Registry Resource Center, to authorize grants for State organ and tissue donor registries, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

JULY 28, 2014

Mr. CLAY introduced the following bill; which was referred to the Committee on Energy and Commerce

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## A BILL

To amend the Public Health Service Act to establish a National Organ and Tissue Donor Registry Resource Center, to authorize grants for State organ and tissue donor registries, 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 “Everson Walls and  
5       Ron Springs Gift for Life Act of 2014”.

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

3 Part H of title III of the Public Health Service Act  
4 (42 U.S.C. 273 et seq.) is amended by inserting after sec-  
5 tion 371A the following:

6 **“SEC. 371B. NATIONAL ORGAN AND TISSUE DONOR REG-**  
7 **ISTRY RESOURCE CENTER.**

8 “(a) IN GENERAL.—The Secretary, acting through  
9 the Administrator of the Health Resources and Services  
10 Administration, shall establish a National Organ and Tis-  
11 sue Donor Registry Resource Center (referred to in this  
12 section as the ‘Center’).

13 “(b) DUTIES.—The Center shall—

14 “(1) advance the development, expansion, and  
15 evaluation of State organ and tissue donor reg-  
16 istries;

17 “(2) facilitate timely access to and exchange of  
18 accurate donor information between State registries  
19 7 days each week on a 24-hour basis;

20 “(3) ensure that State organ and tissue donor  
21 registries funded through section 371C are in com-  
22 pliance with the requirements described in such sec-  
23 tion, including the operating standards described in  
24 section 371C(d);

1           “(4) provide technical assistance to States for  
2 the establishment and operation of State organ and  
3 tissue registries; and

4           “(5) maintain a registry information clearing-  
5 house, including by maintaining a Web site, to col-  
6 lect, synthesize, and disseminate best practices infor-  
7 mation about organ and tissue donor registries.

8           “(c) AUTHORIZATION OF APPROPRIATIONS.—There  
9 is authorized to be appropriated to carry out this section  
10 \$5,000,000 for each of fiscal years 2015 through 2019.”.

11 **SEC. 3. GRANTS FOR STATE ORGAN AND TISSUE DONOR**  
12 **REGISTRIES.**

13           Part H of title III of the Public Health Service Act  
14 (42 U.S.C. 273 et seq.) is amended by inserting after sec-  
15 tion 371B, as inserted by section 2, the following:

16 **“SEC. 371C. GRANTS FOR STATE ORGAN AND TISSUE**  
17 **DONOR REGISTRIES.**

18           “(a) PROGRAM AUTHORIZED.—The Secretary shall  
19 award grants or cooperative agreements to eligible entities  
20 to support the development, enhancement, expansion, and  
21 evaluation of State organ and tissue donor registries.

22           “(b) DEFINITION.—In this section, the term ‘eligible  
23 entity’ means a State agency or a State contracted entity.

24           “(c) USE OF FUNDS.—As a condition on the receipt  
25 of a grant or cooperative agreement under this section,

1 an eligible entity shall agree to use the grant or coopera-  
2 tive agreement—

3 “(1) to develop, expand, or maintain a State  
4 organ and tissue donor registry; and

5 “(2) to establish benchmarks for improvement  
6 in organ and tissue donation in the State.

7 “(d) OPERATING STANDARDS.—As a condition on the  
8 receipt of a grant or cooperative agreement under this sec-  
9 tion for a State organ and tissue donor registry, an eligible  
10 entity shall agree to maintain the registry in accordance  
11 with the following:

12 “(1) The registry must allow a donor or any  
13 other person authorized by the donor to include in  
14 the registry a statement or symbol that the donor  
15 has made, amended, or revoked an anatomical gift.

16 “(2) The registry must be accessible to any  
17 qualified organ procurement organization described  
18 in section 371(b) to allow the organization to obtain  
19 relevant information on the registry to determine, at  
20 or near the death of the donor or a prospective  
21 donor, whether the donor or prospective donor has  
22 made, amended, or revoked an anatomical gift.

23 “(3) The registry must be accessible as de-  
24 scribed in paragraphs (1) and (2) 7 days each week  
25 on a 24-hour basis.

1           “(4) The registry must ensure that personally  
2           identifiable information on the registry about a  
3           donor or prospective donor may not be used or dis-  
4           closed without the express consent of the donor or  
5           prospective donor for any purpose other than to de-  
6           termine, at or near the death of the donor or pro-  
7           spective donor, whether the donor or prospective  
8           donor has made, amended, or revoked an anatomical  
9           gift.

10          “(e) APPLICATION.—To seek a grant or cooperative  
11          agreement under this section, an entity shall submit an  
12          application to the Secretary at such time, in such manner,  
13          and containing such information as the Secretary may rea-  
14          sonably require.

15          “(f) REPORT.—As a condition on the receipt of a  
16          grant or cooperative agreement under this section, not  
17          later than 180 days after receipt of the grant or coopera-  
18          tive agreement, and every 180 days thereafter (through  
19          the date of completion of the activities funded through the  
20          grant or cooperative agreement), an eligible entity shall  
21          prepare and submit a report to the Secretary that—

22                 “(1) describes the manner in which such entity  
23                 has used amounts received through the grant or co-  
24                 operative agreement; and

1           “(2) assesses initiatives that may be replicated  
2           in other States.

3           “(g) AUTHORIZATION OF APPROPRIATIONS.—There  
4 is authorized to be appropriated to carry out this section  
5 \$10,000,000 for each of fiscal years 2015 through 2019.”.

6 **SEC. 4. LIMITATION ON LIABILITY.**

7           Part H of title III of the Public Health Service Act  
8 (42 U.S.C. 273 et seq.) is amended by inserting after sec-  
9 tion 371C, as inserted by section 3, the following:

10 **“SEC. 371D. LIMITATION ON LIABILITY.**

11           “No person may be held civilly liable by reason of  
12 having harvested or taken an individual’s organs or tissues  
13 without having obtained valid consent for the harvesting  
14 or taking, if—

15           “(1) such person has verified that, at the time  
16 of the harvesting or taking, the individual is reg-  
17 istered as a donor with a State organ and tissue  
18 donor registry; and

19           “(2) the harvesting or taking is within the  
20 scope of the consent given by such individual for  
21 purposes of such registration.”.

22 **SEC. 5. STUDY ON FEASIBILITY OF ESTABLISHING A LIVING**  
23 **DONOR DATABASE.**

24           Section 371A of the Public Health Service Act (42  
25 U.S.C. 273a) is amended—

1           (1) by striking “The Secretary may establish”  
2           and inserting “(a) IN GENERAL.—The Secretary  
3           may establish”; and

4           (2) by adding at the end the following:

5           “(b) STUDY.—Not later than 1 year after the date  
6 of the enactment of the Everson Walls and Ron Springs  
7 Gift for Life Act of 2014, the Comptroller General of the  
8 United States shall—

9           “(1) complete a study to determine the feasi-  
10          bility of establishing a living donor database for the  
11          purpose of tracking the short- and long-term health  
12          effects for such donors associated with living organ  
13          donation; and

14          “(2) submit a report to the Congress on the re-  
15          sults of such study.”.

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