

103<sup>D</sup> CONGRESS  
1<sup>ST</sup> SESSION

# S. 1595

To amend the Public Health Service Act to revise and extend the bone marrow donor program, and for other purposes.

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## IN THE SENATE OF THE UNITED STATES

OCTOBER 27 (legislative day, OCTOBER 13), 1993

Mr. KENNEDY (for himself and Mrs. KASSEBAUM) introduced the following bill; which was read twice and referred to the Committee on Labor and Human Resources

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## A BILL

To amend the Public Health Service Act to revise and extend the bone marrow donor program, 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 “Bone Marrow Donor  
5 Program Reauthorization Act of 1993”.

6 **SEC. 2. REAUTHORIZATION.**

7 Section 379 of the Public Health Service Act (42  
8 U.S.C. 274k) is amended—

1 (1) in subsection (a), by adding at the end  
2 thereof the following: “With respect to the board of  
3 directors—

4 “(1) each member of the board shall serve for  
5 a term of 5 years, except that the terms of each  
6 member who is serving on the date of enactment of  
7 the Organ Transplant Program Reauthorization Act  
8 of 1993 shall expire at times determined by the Sec-  
9 retary, in consultation with the board;

10 “(2) a member of the board may continue to  
11 serve after the expiration of the term of such mem-  
12 ber until a successor is appointed; and

13 “(3) to ensure the continuity of the board, not  
14 more than one-fifth of the board shall be composed  
15 of newly appointed members each year.”;

16 (2) in subsection (b)—

17 (A) in paragraph (2), by striking “estab-  
18 lish” and all that follows through “directly as-  
19 sists” and inserting “cooperate with the patient  
20 advocacy and case management office estab-  
21 lished under subsection (j) and make available  
22 information on (A) the resources available  
23 through the National Bone Marrow Donor Pro-  
24 gram, (B) the comparative costs incurred by  
25 patients prior to transplant, and (C) the mar-

1 row donor registries that meet the standards  
2 described in subsection (c)(3) and (d)(1), to as-  
3 sist”;

4 (B) in paragraph (5), to read as follows:

5 “(5) establish a program for the recruitment of  
6 bone marrow donors that includes the compilation  
7 and distribution of informational materials and proc-  
8 esses to educate and update potential donors;”;

9 (C) by redesignating paragraphs (6) and  
10 (7) as paragraphs (7) and (8), respectively; and

11 (D) by inserting after paragraph (5), the  
12 following new paragraph:

13 “(6) regularly update the Registry to account  
14 for changes in potential donor status;”;

15 (3) by redesignating subsection (j) as sub-  
16 section (l);

17 (4) by inserting after subsection (i), the follow-  
18 ing new subsections:

19 “(j) PATIENT ADVOCACY AND CASE MANAGE-  
20 MENT.—

21 “(1) ESTABLISHMENT.—The Secretary shall by  
22 grant or contract establish and maintain an office of  
23 patient advocacy and case management that meets  
24 the requirements of this subsection.

1           “(2) PROVISIONS RELATING TO GRANTS AND  
2 CONTRACTS.—

3           “(A) APPLICATION.—To be eligible for a  
4 grant or contract under this subsection an en-  
5 tity shall prepare and submit to the Secretary  
6 for approval an application that shall be in such  
7 form, submitted in such manner, and contain  
8 such information as the Secretary shall by regu-  
9 lation prescribe.

10           “(B) LIMITATIONS.—A grant or contract  
11 under this subsection shall be for a period of 3  
12 years. No grant or contract may exceed  
13 \$500,000 for any such year.

14           “(3) FUNCTIONS.—The office established under  
15 paragraph (1) shall—

16           “(A) be headed by a director who shall  
17 serve as an advocate on behalf of—

18           “(i) individuals who are registered  
19 with the Registry to search for a bio-  
20 logically unrelated bone marrow donor; and

21           “(ii) the physicians involved;

22           “(B) establish and maintain a system for  
23 patient advocacy that directly assists patients,  
24 their families, and their physicians in a search  
25 for an unrelated donor;

1           “(C) provide individual case management  
2 services to directly assist individuals and physi-  
3 cians referred to in subparagraph (A), includ-  
4 ing—

5                   “(i) individualized case assessment,  
6 tracking of preliminary search through ac-  
7 tivation, and follow up when the search  
8 process is interrupted or discontinued;

9                   “(ii) informing individuals and physi-  
10 cians of progress made in searching for ap-  
11 propriate donors; and

12                   “(iii) identifying and resolving individ-  
13 ual search problems or concerns;

14           “(D) collect and analyze data concerning  
15 the number and percentage of individuals pro-  
16 ceeding from preliminary to formal search and  
17 the number and percentage of patients unable  
18 to complete the search process; and

19           “(E) survey patients to evaluate how well  
20 such patients are being served and make rec-  
21 ommendations for streamlining the search proc-  
22 ess.

23           “(4) EVALUATION.—

24                   “(A) IN GENERAL.—The Secretary shall  
25 evaluate the system established under para-

1 graph (1) and make recommendations to Con-  
2 gress concerning the success or failure of such  
3 system in improving patient satisfaction, and  
4 any impact the system has had on assisting in-  
5 dividuals in proceeding to transplant.

6 “(B) REPORT.—Not later than January 1,  
7 1995, the Secretary shall prepare and submit to  
8 the Committee on Energy and Commerce of the  
9 House of Representatives and the Committee  
10 on Labor and Human Resources of the Senate  
11 a report concerning the evaluation conducted  
12 under subparagraph (A), including the rec-  
13 ommendations developed under such subpara-  
14 graph.

15 “(k) INFORMATION AND EDUCATION PROGRAM.—

16 “(1) IN GENERAL.—The Secretary may award  
17 grants to, and enter into contracts with, public or  
18 nonprofit private entities for the purpose of increas-  
19 ing bone marrow donation by enabling such entities  
20 to—

21 “(A) plan and conduct programs to provide  
22 information and education to the public on the  
23 need for donations of bone marrow;

24 “(B) train individuals in requesting such  
25 donations; and

1           “(C) test and enroll marrow donors.

2           “(2) ENROLLMENT.—Donors enrolled under  
3 this subsection with Federal Government funds must  
4 be enrolled with the Registry described in section  
5 379. Such donors may be enrolled at other reg-  
6 istries.

7           “(3) PRIORITIES.—In awarding grants and con-  
8 tracts under paragraph (1), the Secretary shall give  
9 priority to carrying out the purposes described in  
10 such paragraph with respect to minority populations  
11 and other populations that donate at a rate lower  
12 than that of the general public.”; and

13           (5) in subsection (l) (as so redesignated), by  
14 striking “1991” and all that follows and inserting  
15 “1994, and such sums as may be necessary for each  
16 of the fiscal years 1995 and 1996.”.

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