

103^D CONGRESS
1ST SESSION

S. 1774

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

IN THE SENATE OF THE UNITED STATES

NOVEMBER 22, 1993

Mr. KENNEDY (for himself and Mrs. KASSEBAUM) introduced the following bill; which was read twice, considered, read the third time, and passed

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 (a) ESTABLISHMENT OF REGISTRY.—Section 379(a)
8 of the Public Health Service Act (42 U.S.C. 274k(a)) is
9 amended by adding at the end thereof the following: “With
10 respect to the board of directors—

1 “(1) each member of the board shall serve for
2 a term of 5 years, except that the terms of each
3 member who is serving on the date of enactment of
4 the Bone Marrow Donor Program Reauthorization
5 Act of 1993 shall expire at times determined by the
6 Secretary, in consultation with the board;

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

10 “(3) to ensure the continuity of the board, not
11 more than one-fifth of the board shall be composed
12 of newly appointed members each year.”.

13 (b) PROGRAM FOR RECRUITMENT OF DONORS.—Sec-
14 tion 379(b) of such Act (42 U.S.C. 274k(b)) is amended—

15 (1) in paragraph (5) to read as follows:

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

20 (2) by redesignating paragraphs (6) and (7) as
21 paragraphs (7) and (8), respectively; and

22 (3) by inserting after paragraph (5), the follow-
23 ing new paragraph:

24 “(6) regularly update the Registry to account
25 for changes in potential donor status;”.

1 (c) INFORMATION AND EDUCATION PROGRAM.—Sec-
2 tion 379 of such Act (42 U.S.C. 274k) is amended—

3 (1) by redesignating subsection (j) as sub-
4 section (k);

5 (2) by inserting after subsection (i), the follow-
6 ing new subsection:

7 “(j) INFORMATION AND EDUCATION PROGRAM.—

8 “(1) IN GENERAL.—The Secretary may award
9 grants to, and enter into contracts with, public or
10 nonprofit private entities for the purpose of increas-
11 ing bone marrow donation by enabling such entities
12 to—

13 “(A) plan and conduct programs to provide
14 information and education to the public on the
15 need for donations of bone marrow;

16 “(B) train individuals in requesting such
17 donations; and

18 “(C) test and enroll marrow donors.

19 “(2) PRIORITIES.—In awarding grants and con-
20 tracts under paragraph (1), the Secretary shall give
21 priority to carrying out the purposes described in
22 such paragraph with respect to minority popu-
23 lations.”; and

24 (3) in subsection (k) (as so redesignated), by
25 striking “1991” and all that follows and inserting

1 “1994, and such sums as may be necessary for each
2 of the fiscal years 1995 and 1996.”.

3 (d) PATIENT ADVOCACY AND CASE MANAGEMENT.—

4 (1) IN GENERAL.—Section 379 of such Act (42
5 U.S.C. 274k), as amended by subsection (c), is
6 amended—

7 (A) by redesignating subsection (k) as sub-
8 section (l); and

9 (B) by inserting after subsection (j), the
10 following new subsection:

11 “(k) PATIENT ADVOCACY AND CASE MANAGE-
12 MENT.—

13 “(1) ESTABLISHMENT.—The Secretary shall by
14 grant or contract establish and maintain an office of
15 patient advocacy and case management that meets
16 the requirements of this subsection.

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

19 “(A) APPLICATION.—To be eligible for a
20 grant or contract under this subsection an en-
21 tity shall prepare and submit to the Secretary
22 for approval an application that shall be in such
23 form, submitted in such manner, and contain
24 such information as the Secretary shall by regu-
25 lation prescribe.

1 “(B) LIMITATIONS.—A grant or contract
2 under this subsection shall be for a period of 3
3 years. No grant or contract may exceed
4 \$500,000 for any such year.

5 “(3) FUNCTIONS.—The office established under
6 paragraph (1) shall—

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

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

12 “(ii) the physicians involved;

13 “(B) establish and maintain a system for
14 patient advocacy that directly assists patients,
15 their families, and their physicians in a search
16 for an unrelated donor;

17 “(C) provide individual case management
18 services to directly assist individuals and physi-
19 cians referred to in subparagraph (A), includ-
20 ing—

21 “(i) individualized case assessment,
22 tracking of preliminary search through ac-
23 tivation, and followup when the search
24 process is interrupted or discontinued;

1 “(ii) informing individuals and physi-
2 cians of progress made in searching for ap-
3 propriate donors; and

4 “(iii) identifying and resolving individ-
5 ual search problems or concerns;

6 “(D) collect and analyze data concerning
7 the number and percentage of individuals pro-
8 ceeding from preliminary to formal search and
9 the number and percentage of patients unable
10 to complete the search process; and

11 “(E) survey patients to evaluate how well
12 such patients are being served and make rec-
13 ommendations for streamlining the search proc-
14 ess.

15 “(4) EVALUATION.—

16 “(A) IN GENERAL.—The Secretary shall
17 evaluate the system established under para-
18 graph (1) and make recommendations to Con-
19 gress concerning the success or failure of such
20 system in improving patient satisfaction, and
21 any impact the system has had on assisting in-
22 dividuals in proceeding to transplant.

23 “(B) REPORT.—Not later than April 1,
24 1996, the Secretary shall prepare and submit to
25 the Committee on Energy and Commerce of the

1 House of Representatives and the Committee
2 on Labor and Human Resources of the Senate
3 a report concerning the evaluation conducted
4 under subparagraph (A), including the rec-
5 ommendations developed under such subpara-
6 graph.”.

7 (2) REGISTRY FUNCTIONS.—Section 379(b)(2)
8 of such Act (42 U.S. C. 274k(b)(2)) is amended by
9 striking “establish” and all that follows through “di-
10 rectly assists” and inserting “cooperate with the pa-
11 tient advocacy and case management office estab-
12 lished under subsection (j) and make available infor-
13 mation on (A) the resources available through the
14 National Bone Marrow Donor Program, (B) the
15 comparative costs incurred by patients prior to
16 transplant, and (C) the marrow donor registries that
17 meet the standards described in subsection (c)(3)
18 and (d)(1), to assist”.

19 (3) EFFECTIVE DATE.—The amendments made
20 by this subsection shall take effect on April 1, 1995.

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