

108TH CONGRESS  
1ST SESSION

# H. R. 3034

To amend the Public Health Service Act to reauthorize the National Bone Marrow Donor Registry, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 5, 2003

Mr. YOUNG of Florida (for himself, Mr. BILIRAKIS, and Mr. TOWNS) 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 reauthorize the National Bone Marrow Donor 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 “National Bone Marrow  
5 Donor Registry Reauthorization Act”.

6 **SEC. 2. NATIONAL BONE MARROW DONOR REGISTRY.**

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

9 (1) in subsection (a)—

1 (A) in paragraph (1), by striking “except  
2 that” and all that follows and inserting “except  
3 that—

4 “(A) such limitations shall not apply to the  
5 Chair of the board (or the Chair-elect) or to the  
6 member of the board who most recently served  
7 as the Chair; and

8 “(B) 1 additional consecutive 2-year term  
9 may be served by any member of the board who  
10 has no employment, governance, or financial af-  
11 filiation with any donor center, recruitment  
12 group, transplant center, or cord blood bank.”;

13 (B) in paragraph (4)—

14 (i) by striking “the Naval Medical Re-  
15 search and Development Command” and  
16 inserting “Department of Defense Marrow  
17 Donor Recruitment and Research Program  
18 operated by the Department of the Navy”;  
19 and

20 (ii) by striking “Organ” after “Divi-  
21 sion of”;

22 (2) in subsection (b)—

23 (A) in paragraph (4), by inserting “at  
24 least” before “annually”;

1 (B) in paragraph (7), by striking “and  
2 comparisons of transplant centers regarding  
3 search and other costs that prior to transplan-  
4 tation are charged to patients by transplant  
5 centers; and”;

6 (C) in paragraph (8), by inserting “and  
7 outreach” after “and demonstration”;

8 (D) at the end of paragraph (8), by strik-  
9 ing the period and inserting a semicolon;

10 (E) by redesignating paragraphs (3)  
11 through (8) as paragraphs (4) through (9);

12 (F) by inserting after paragraph (2), the  
13 following:

14 “(3) maintain and expand medical emergency  
15 contingency response capabilities in concert with  
16 Federal programs for response to threats of use of  
17 terrorist or military weapons that can damage mar-  
18 row, such as ionizing radiation or chemical agents  
19 containing mustard, so that the capability of sup-  
20 porting patients with marrow damage from disease  
21 can be used to support casualties with marrow dam-  
22 age;” and

23 (G) by adding at the end the following:

24 “(10) conduct and support research to improve  
25 the availability, efficiency, safety, and cost of trans-

1 plants from unrelated donors and the effectiveness  
2 of Registry operations;

3 “(11) increase the number of umbilical cord  
4 blood units listed in the Registry and assist cord  
5 blood banks in the Registry program in accordance  
6 with subsection (c); and

7 “(12) establish bylaws and procedures—

8 “(A) to prohibit any member of the board  
9 of directors of the Registry who has an employ-  
10 ment, governance, or financial affiliation with a  
11 donor center, recruitment group, transplant  
12 center, or cord blood bank from participating in  
13 any decision that materially affects the center,  
14 recruitment group, or cord blood bank; and

15 “(B) to limit the number of members of  
16 the board with any such affiliation.”;

17 (3) in subsection (c)—

18 (A) in clause (ii) of paragraph (2)(A), by  
19 striking “, including providing updates”; and

20 (B) in paragraph (3), by striking “the  
21 availability, as a potential treatment option, of  
22 receiving a transplant of bone marrow from an  
23 unrelated donor” and inserting “transplants  
24 from unrelated donors as a treatment option

1 and resources for identifying and evaluating  
2 other therapeutic alternatives”;

3 (4) in subsection (d)—

4 (A) in paragraph (2)(C), by inserting “and  
5 assist with information regarding third party  
6 payor matters” after “ongoing search for a  
7 donor”;

8 (B) in paragraph (2)(F)—

9 (i) by redesignating clause (v) as  
10 clause (vi); and

11 (ii) by inserting after clause (iv) the  
12 following:

13 “(v) Information concerning issues  
14 that patients may face after a transplant  
15 regarding continuity of care and quality of  
16 life.”; and

17 (C) in paragraph (3)(B), by striking “Of-  
18 fice may” and inserting “Office shall”;

19 (5) in subsection (g), by striking “the bone  
20 marrow donor program of the Department of the  
21 Navy” and inserting “Department of Defense Mar-  
22 row Donor Recruitment and Research Program op-  
23 erated by the Department of Navy”;

24 (6) in subsection (h)—

1 (A) by striking “APPLICATION.—” and in-  
2 serting “CONTRACTS.—”;

3 (B) by striking “To be eligible” and insert-  
4 ing the following: “(1) APPLICATION.—To be  
5 eligible”; and

6 (C) by adding at the end the following:

7 “(2) CONSIDERATIONS.—In awarding contracts  
8 under this section, the Secretary shall give substan-  
9 tial weight to the continued safety of donors and pa-  
10 tients and other factors deemed appropriate by the  
11 Secretary.”;

12 (7) in subsection (i), by striking “include” and  
13 inserting “be”; and

14 (8) by striking subsection (l).

15 (b) BONE MARROW SCIENTIFIC REGISTRY.—Section  
16 379A of the Public Health Service Act (42 U.S.C. 274l)  
17 is amended—

18 (1) in subsection (a), by adding at the end the  
19 following: “The scientific registry shall participate in  
20 medical research that has the potential to improve  
21 transplant outcomes.”;

22 (2) in subsection (c), by striking “Each such re-  
23 port shall in addition include the data required in  
24 section 379(l) (relating to pretransplant costs)”;

25 (3) adding after subsection (c):

1       “(d) PUBLICLY AVAILABLE DATA.—The scientific  
2 registry shall make relevant scientific information not con-  
3 taining personal identifiers available to the public in the  
4 form of summaries and data sets to encourage medical re-  
5 search and to provide information to transplant programs,  
6 physicians, and patients.”

7       (c) BONE MARROW AND MARROW DEFINED.—Part  
8 I of title III of the Public Health Service Act (42 U.S.C.  
9 274k et seq.) is amended—

10           (1) by redesignating section 379B as section  
11       379C; and

12           (2) by inserting after section 379A the fol-  
13       lowing:

14       **“SEC. 379B. BONE MARROW AND MARROW DEFINED.**

15       “For purposes of this part, the terms ‘bone marrow’  
16 and ‘marrow’ include bone marrow and any other source  
17 of hematopoietic progenitor cells the acquisition or use of  
18 which is not inconsistent with Federal law.”.

19       (d) AUTHORIZATION OF APPROPRIATIONS.—Section  
20 379C of the Public Health Service Act, as redesignated  
21 by subsection (c), is amended to read as follows:

22       **“SEC. 379C. AUTHORIZATION OF APPROPRIATIONS.**

23       “(a) IN GENERAL.—For the purpose of carrying out  
24 this part, there are authorized to be appropriated  
25 \$32,000,000 for fiscal year 2004, and such sums as may

1 be necessary for each of the fiscal years 2005 through  
2 2008.

3       “(b) EMERGENCY CONTINGENCY RESPONSE CAPA-  
4 BILITIES.—In addition to any amounts authorized to be  
5 appropriated under subsection (a), there are authorized to  
6 be appropriated such sums as may be necessary for the  
7 maintenance and expansion of emergency contingency re-  
8 sponse capabilities under section 379(b)(3).”.

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