AUTHENTICATED
U.S. GOVERNMENT
INFORMATION
GPO

108TH CONGRESS
1st Session
HOUSE OF REPRESENTATIVES
REPORT
108–276

NATIONAL BONE MARROW DONOR REGISTRY REAUTHORIZATION ACT

SEPTEMBER 17, 2003.—Committed to the Committee of the Whole House on the State of the Union and ordered to be printed

Mr. TAUZIN, from the Committee on Energy and Commerce, submitted the following

R E P O R T

[To accompany H.R. 3034]

[Including cost estimate of the Congressional Budget Office]

The Committee on Energy and Commerce, to whom was referred the bill (H.R. 3034) to amend the Public Health Service Act to reauthorize the National Bone Marrow Donor Registry, and for other purposes, having considered the same, report favorably thereon with an amendment and recommend that the bill as amended do pass.

CONTENTS

	Page
Amendment	2
Purpose and Summary	3
Background and Need for Legislation	3
Hearings	4
Committee Consideration	4
Committee Votes	4
Committee Oversight Findings	4
Statement of General Performance Goals and Objectives	4
New Budget Authority, Entitlement Authority, and Tax Expenditures	4
Committee Cost Estimate	5
Congressional Budget Office Estimate	5
Federal Mandates Statement	6
Advisory Committee Statement	6
Constitutional Authority Statement	6
Applicability to Legislative Branch	7
Section-by-Section Analysis of the Legislation	7
Changes in Existing Law Made by the Bill, as Reported	8

★ 19–006

AMENDMENT

The amendment is as follows:
Strike all after the enacting clause and insert the following:

SECTION 1. SHORT TITLE.

This Act may be cited as the "National Bone Marrow Donor Registry Reauthorization Act".

SEC. 2. NATIONAL BONE MARROW DONOR REGISTRY.

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

(1) in subsection (a)—

(A) in paragraph (1), by striking "except that" and all that follows and inserting "except that—

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

"(B) 1 additional consecutive 2-year term may be served by any member of the board who has no employment, governance, or financial affiliation with any donor center, recruitment group, transplant center, or cord blood bank."; and

(B) in paragraph (4)—

(i) by striking "the Naval Medical Research and Development Command" and inserting "the Department of Defense Marrow Donor Recruitment and Research Program operated by the Department of the Navy"; and

(ii) by striking "Organ" after "Division of";

(2) in subsection (b)—

(A) in paragraph (4), by inserting "at least" before "annually";

(B) in paragraph (7), by striking "and comparisons of transplant centers regarding search and other costs that prior to transplantation are charged to patients by transplant centers; and";

(C) in paragraph (8), by inserting "and outreach" after "and demonstration";

(D) at the end of paragraph (8), by striking the period and inserting a semicolon;

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

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

"(3) maintain and expand medical emergency contingency response capabilities in concert with Federal programs for response to threats of use of terrorist or military weapons that can damage marrow, such as ionizing radiation or chemical agents containing mustard, so that the capability of supporting patients with marrow damage from disease can be used to support casualties with marrow damage;"; and

(G) by adding at the end the following:

"(10) conduct and support research to improve the availability, efficiency, safety, and cost of transplants from unrelated donors and the effectiveness of Registry operations;

"(11) increase the number of umbilical cord blood units listed in the Registry and assist cord blood banks in the Registry program in accordance with subsection (c); and

"(12) establish bylaws and procedures—

"(A) to prohibit any member of the board of directors of the Registry who has an employment, governance, or financial affiliation with a donor center, recruitment group, transplant center, or cord blood bank from participating in any decision that materially affects the center, recruitment group, transplant center, or cord blood bank; and

"(B) to limit the number of members of the board with any such affiliation.";

(3) in subsection (c)—

(A) in clause (ii) of paragraph (2)(A), by striking ", including providing updates"; and

(B) in paragraph (3), by striking "the availability, as a potential treatment option, of receiving a transplant of bone marrow from an unrelated donor" and inserting "transplants from unrelated donors as a treatment option and resources for identifying and evaluating other therapeutic alternatives";

(4) in subsection (d)—

(A) in paragraph (2)(C), by inserting "and assist with information regarding third party payor matters" after "ongoing search for a donor";

(B) in paragraph (2)(F)—

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

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

"(v) Information concerning issues that patients may face after a transplant regarding continuity of care and quality of life."; and

(C) in paragraph (3)(B), by striking "Office may" and inserting "Office shall";

(5) in subsection (g), by striking "the bone marrow donor program of the Department of the Navy" and inserting "the Department of Defense Marrow Donor Recruitment and Research Program operated by the Department of the Navy";

(6) in subsection (h)—

(A) by striking "APPLICATION.—" and inserting "CONTRACTS.—";

(B) by striking "To be eligible" and inserting the following:

"(1) APPLICATION.—To be eligible"; and

(C) by adding at the end the following:

"(2) CONSIDERATIONS.—In awarding contracts under this section, the Secretary shall give substantial weight to the continued safety of donors and patients and other factors deemed appropriate by the Secretary.";

(7) in subsection (i), by striking "include" and inserting "be"; and

(8) by striking subsection (l).

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

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

(2) in subsection (c), by striking "Each such report shall in addition include the data required in section 379(l) (relating to pretransplant costs)."; and

(3) by adding after subsection (c) the following:

"(d) PUBLICLY AVAILABLE DATA.—The scientific registry shall make relevant scientific information not containing individually identifiable information available to the public in the form of summaries and data sets to encourage medical research and to provide information to transplant programs, physicians, and patients.".

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

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

(2) by inserting after section 379A the following:

"SEC. 379B. BONE MARROW AND MARROW DEFINED.

"For purposes of this part, the terms 'bone marrow' and 'marrow' include bone marrow and any other source of hematopoietic progenitor cells the acquisition or use of which is not inconsistent with Federal law.".

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

"SEC. 379C. AUTHORIZATION OF APPROPRIATIONS.

"(a) IN GENERAL.—For the purpose of carrying out this part, there are authorized to be appropriated $32,000,000 for fiscal year 2004, and such sums as may be necessary for each of the fiscal years 2005 through 2008.

"(b) EMERGENCY CONTINGENCY RESPONSE CAPABILITIES.—In addition to the amounts authorized to be appropriated under subsection (a), there are authorized to be appropriated such sums as may be necessary for the maintenance and expansion of emergency contingency response capabilities under section 379(b)(3).".

PURPOSE AND SUMMARY

H.R. 3034 amends section 379 of the Public Health Service Act to reauthorize the national bone marrow donor registry.

BACKGROUND AND NEED FOR LEGISLATION

Bone marrow transplants are often one of the last options available to patients struggling to fight debilitating and often terminal diseases. Unfortunately, finding a bone marrow match is rather difficult. In fact, every year, nearly two-thirds of patients in need of a bone marrow transplant will not find a marrow donor match

within their family and must rely on the help of strangers. The national bone marrow donor registry facilitates marrow and cord blood transplants for patients with life-threatening diseases who do not have matching donors in their families.

Federal support began in 1986 when Congress directed the U.S. Navy to establish a national registry of bone marrow donors. The following year, as part of the Health Omnibus Programs Extension Act (P.L. 100–607), Congress expanded the bone marrow registry by requiring the Department of Health and Human Services (HHS) to assume the responsibility of managing the bone marrow registry. Currently, HHS contracts with the National Bone Marrow Donor Program, a non-profit organization based in Minneapolis, MN, to operate the program. Congress last reauthorized the national bone marrow donor registry in 1998. Authorization of appropriations for the program expires in fiscal year 2003.

H.R. 3034, the National Bone Marrow Donor Registry Reauthorization Act, reauthorizes the registry for an additional five-year period.

HEARINGS

The Committee on Energy and Commerce has not held hearings on the legislation.

COMMITTEE CONSIDERATION

On September 10, 2003, the Full Committee met in open markup session and favorably ordered H.R. 3034 reported to the House, as amended, by a voice vote, a quorum being present.

COMMITTEE VOTES

Clause 3(b) of rule XIII of the Rules of the House of Representatives requires the Committee to list the record votes on the motion to report legislation and amendments thereto. There were no record votes taken in connection with ordering H.R. 3034 reported. A motion by Mr. Tauzin to order H.R. 3034 reported to the House, as amended, was agreed to by a voice vote.

COMMITTEE OVERSIGHT FINDINGS

Pursuant to clause 3(c)(1) of rule XIII of the Rules of the House of Representatives, the Committee has not held oversight or legislative hearings on this legislation.

STATEMENT OF GENERAL PERFORMANCE GOALS AND OBJECTIVES

The goal of H.R. 3034 is to reauthorize the national bone marrow donor registry for an additional five-year period.

NEW BUDGET AUTHORITY, ENTITLEMENT AUTHORITY, AND TAX EXPENDITURES

In compliance with clause 3(c)(2) of rule XIII of the Rules of the House of Representatives, the Committee finds that H.R. 3034, the National Bone Marrow Donor Registry Act, would result in no new or increased budget authority, entitlement authority, or tax expenditures or revenues.

COMMITTEE COST ESTIMATE

The Committee adopts as its own the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974.

CONGRESSIONAL BUDGET OFFICE ESTIMATE

Pursuant to clause 3(c)(3) of rule XIII of the Rules of the House of Representatives, the following is the cost estimate provided by the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974:

U.S. CONGRESS,
CONGRESSIONAL BUDGET OFFICE,
Washington, DC, September 16, 2003.

Hon. W.J. "BILLY" TAUZIN,
Chairman, Committee on Energy and Commerce,
House of Representatives, Washington, DC.

DEAR MR. CHAIRMAN: The Congressional Budget Office has prepared the enclosed cost estimate for H.R. 3034, the National Bone Marrow Donor Registry Reauthorization Act.

If you wish further details on this estimate, we will be pleased to provide them. The CBO staff contact is Margaret Nowak.

Sincerely,

DOUGLAS HOLTZ-EAKIN,
Director.

Enclosure.

H.R. 3034—National Bone Marrow Donor Registry Reauthorization Act

Summary: H.R. 3034 would amend the Public Health Service Act to reauthorize and amend the National Bone Marrow Donor Registry operated by the Health Resources and Services Administration (HRSA). The registry operates a system for finding marrow donors suitably matched to unrelated recipients for bone marrow transplantation. The bill would reauthorize funding for the registry through 2008. H.R. 3034 also would alter some of the term-limit requirements and establish conflict interest regulations for board members involved in the administration of donor centers. In addition, the bill would require more frequent updates of information on potential donors and would expand contingency plans for safeguarding donated marrow in the event of a terrorist or military attack.

CBO estimates that implementing H.R. 3034 would cost $10 million in 2004 and $145 million over the 2004–2008 period, assuming the appropriation of the necessary amounts. The legislation would not affect direct spending or receipts.

The bill contains no intergovernmental or private-sector mandates as defined in the Unfunded Mandates Reform Act (UMRA) and would impose no costs on State, local, or tribal governments.

Estimated cost to the Federal Government: The estimated budgetary impact of H.R. 3034 is shown in the following table. The costs of this legislation fall within budget function 550 (health).

	By fiscal year, in millions of dollars—					
	2003	2004	2005	2006	2007	2008
SPENDING SUBJECT TO APPROPRIATION						
Spending Under Current Law:						
Budget Authority [1]	22	0	0	0	0	0
Estimated Outlays	9	10	4	2	0	0
Proposed Changes [2]:						
Estimated Authorization Level	0	34	35	37	41	45
Estimated Outlays	0	10	25	33	37	40
Spending Under H.R. 3034:						
Estimated Authorization Level [1]	22	34	35	37	41	45
Estimated Outlays	9	21	29	34	37	40

[1] The 2003 level is the amount appropriated for that year for the National Bone Marrow Donor Registry.
[2] Including adjustments for anticipated inflation, the estimated outlay changes would total $145 million over the 2004–2008 period. Without such adjustments, the five-year total would be $133 million.

Basis of estimate: H.R. 3034 would reauthorize funding for the National Bone Marrow Donor Registry through 2008. The registry operates a system for finding marrow donors suitably match to unrelated recipients for bone marrow transplantation. H.R. 3034 would authorize the appropriation of $32 million in 2004 and such sums as necessary through 2008 for operating the registry. Based on historical spending patterns for the registry, CBO estimates that operating it would cost $9 million in 2004 and $136 million over the 2004–2008 period, assuming appropriation of the authorized amounts.

The bill also would expand the functions of the registry to maintain and expand medical emergency contingency plans for safeguarding donated marrow in the event of a terrorist or military attack. Based on information provided by HRSA, CBO estimates that implementing the contingency plans in H.R. 3034 would cost $1 million in 2004 and $9 million over the 2004–2008 period, assuming the appropriation of the necessary amounts.

Intergovernmental and private-sector impact: H.R. 3034 contains no intergovernmental or private-sector mandates as defined in UMRA and would not affect the budgets of State, local, or tribal governments.

Estimate prepared by: Federal Costs: Margaret Nowak. Impact on State, local and tribal governments: Leo Lex. Impact on the private sector: Samuel Kina.

Estimate approved by: Peter H. Fontaine. Deputy Assistant Director for Budget Analysis.

FEDERAL MANDATES STATEMENT

The Committee adopts as its own the estimate of Federal mandates prepared by the Director of the Congressional Budget Office pursuant to section 423 of the Unfunded Mandates Reform Act.

ADVISORY COMMITTEE STATEMENT

No advisory committees within the meaning of section 5(b) of the Federal Advisory Committee Act were created by this legislation.

CONSTITUTIONAL AUTHORITY STATEMENT

Pursuant to clause 3(d)(1) of rule XIII of the Rules of the House of Representatives, the Committee finds that the Constitutional authority for this legislation is provided in Article I, section 8, clause

3, which grants Congress the power to regulate commerce with foreign nations, among the several States, and with the Indian tribes.

APPLICABILITY TO LEGISLATIVE BRANCH

The Committee finds that the legislation does not relate to the terms and conditions of employment or access to public services or accommodations within the meaning of section 102(b)(3) of the Congressional Accountability Act.

SECTION-BY-SECTION ANALYSIS OF THE LEGISLATION

Section 1. Short title

Section 1 designates the short title as the "National Bone Marrow Registry Reauthorization Act."

Section 2. National bone marrow donor registry

Section 2 amends section 379 of the Public Health Service Act to add more procedures for rotating the board of directors of the national bone marrow donor registry. It provides that a board member may serve one additional consecutive two-year term if the board member has no employment, governance, or financial affiliation with any donor center, recruitment group, transplant center, or cord blood bank.

Section 2 corrects references to offices within the Department of the Navy and the Health Resources and Service Administration, the two federal agencies that manage bone marrow registries.

Section 2 also amends the functions of the national bone marrow registry to reflect new directions the national bone marrow registry is undertaking to improve its capabilities. Specifically, this section directs the registry to maintain and expand medical response capabilities in concert with federal programs for responding to terrorist threats that can damage marrow. Additional appropriations for this purpose may be awarded if the Secretary deems it necessary to significantly expand this function of the registry. The registry must conduct and support research to improve the availability, efficiency, safety, and cost of transplants from unrelated donors and the effectiveness of registry operations. Because of this new language, this section deletes a duplicative existing requirement that the registry make comparisons of transplant centers regarding search and other costs that prior to transplantation are charged to patients by transplant centers. The registry must at least annually update information to account for changes in the status of individuals as potential donors of bone marrow. The registry is also directed to increase the number of umbilical cord blood units listed in the registry and assist cord blood banks in the registry program. Finally, the registry must establish bylaws and procedures to limit the affiliation and membership to the board of directors to anyone who has an employment governance, or financial affiliation with a donor center, recruitment group, transplant center, or cord blood bank from participating in any decision that will bring material gain.

Section 2 also directs the registry to provide information to physicians, other health care professionals, and the public regarding transplants from unrelated donors. In terms of patient advocacy, the registry is directed to also assist patients with information regarding third party payor matter.

In addition, this section permits private nonprofit entities to enter into contracts with the registry. In awarding contracts, the Secretary must give substantial weight to the continued safety of donors and patients and other factors deemed appropriate by the Secretary. It also deletes a duplicative reporting requirement regarding transplantation costs.

Section 2 expands the activities of the bone marrow scientific registry, a registry of information relating to patients who have been recipients of transplant bone marrow from a biologically unrelated donor, to require the registry to participate in medical research that has the potential to improve transplant outcomes. The registry is also required to make relevant scientific information not containing individually identifiable information available to the public in the form of summaries and data sets to encourage medical research and to provide information to transplant programs, physicians, and patients.

Section 2 formally defines the terms "bone marrow" and "marrow" to include bone marrow and any other source of hematopoietic progenitor cells the acquisition or use of which is not inconsistent with Federal law.

Finally, section 2 authorizes the appropriation of $32,000,000 for fiscal year 2004 and such sums as may be necessary for each of the years 2005 through 2008.

CHANGES IN EXISTING LAW MADE BY THE BILL, AS REPORTED

In compliance with clause 3(e) of rule XIII of the Rules of the House of Representatives, changes in existing law made by the bill, as reported, are shown as follows (existing law proposed to be omitted is enclosed in black brackets, new matter is printed in italic, existing law in which no change is proposed is shown in roman):

PUBLIC HEALTH SERVICE ACT

* * * * * * *

TITLE III—GENERAL POWERS AND DUTIES OF PUBLIC HEALTH SERVICE

* * * * * * *

PART I—NATIONAL BONE MARROW DONOR REGISTRY

SEC. 379. NATIONAL REGISTRY.

(a) ESTABLISHMENT.—The Secretary shall by contract establish and maintain a National Bone Marrow Donor Registry (referred to in this part as the "Registry") that has the purpose of increasing the number of transplants for recipients suitably matched to biologically unrelated donors of bone marrow, and that meets the requirements of this section. The Registry shall be under the general supervision of the Secretary, and under the direction of a board of directors meeting the following requirements:

(1) Each member of the board shall serve for a term of 2 years, and each such member may serve as many as 3 consecutive 2-year terms, [except that such limitations shall not apply

to the Chair of the board (or the Chair-elect) or to the member of the board who most recently served as the Chair.] *except that—*

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

(B) 1 additional consecutive 2-year term may be served by any member of the board who has no employment, governance, or financial affiliation with any donor center, recruitment group, transplant center, or cord blood bank.

* * * * * * *

(4) The membership of the board shall include representatives of marrow donor centers and marrow transplant centers; recipients of a bone marrow transplant; persons who require or have required such a transplant; family members of such a recipient or family members of a patient who has requested the assistance of the Registry in searching for an unrelated donor of bone marrow; persons with expertise in the social sciences; and members of the general public; and in addition nonvoting representatives from [the Naval Medical Research and Development Command] *the Department of Defense Marrow Donor Recruitment and Research Program operated by the Department of the Navy* and from the Division of [Organ] Transplantation of the Health Resources and Services Administration.

(b) FUNCTIONS.—The Registry shall—

(1) * * *

* * * * * * *

(3) maintain and expand medical emergency contingency response capabilities in concert with Federal programs for response to threats of use of terrorist or military weapons that can damage marrow, such as ionizing radiation or chemical agents containing mustard, so that the capability of supporting patients with marrow damage from disease can be used to support casualties with marrow damage;

[(3)] *(4)* carry out informational and educational activities in accordance with subsection (c);

[(4)] *(5) at least* annually update information to account for changes in the status of individuals as potential donors of bone marrow;

[(5)] *(6)* provide for a system of patient advocacy through the office established under subsection (d);

[(6)] *(7)* provide case management services for any potential donor of bone marrow to whom the Registry has provided a notice that the potential donor may be suitably matched to a particular patient (which services shall be provided through a mechanism other than the system of patient advocacy under subsection (d)), and conduct surveys of donors and potential donors to determine the extent of satisfaction with such services and to identify ways in which the services can be improved;

[(7)] *(8)* with respect to searches for unrelated donors of bone marrow that are conducted through the system under paragraph (1), collect and analyze and publish data on the number and percentage of patients at each of the various stages of the search process, including data regarding the fur-

thest stage reached; the number and percentage of patients who are unable to complete the search process, and the reasons underlying such circumstances; [and comparisons of transplant centers regarding search and other costs that prior to transplantation are charged to patients by transplant centers; and]

[(8)] *(9)* support studies and demonstration *and outreach* projects for the purpose of increasing the number of individuals, especially minorities, who are willing to be marrow donors[.]*;*

(10) conduct and support research to improve the availability, efficiency, safety, and cost of transplants from unrelated donors and the effectiveness of Registry operations;

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

(12) establish bylaws and procedures—

(A) to prohibit any member of the board of directors of the Registry who has an employment, governance, or financial affiliation with a donor center, recruitment group, transplant center, or cord blood bank from participating in any decision that materially affects the center, recruitment group, transplant center, or cord blood bank; and

(B) to limit the number of members of the board with any such affiliation.

(c) RECRUITMENT; PRIORITIES; INFORMATION AND EDUCATION.—

(1) * * *

(2) INFORMATION AND EDUCATION REGARDING RECRUITMENT; TESTING AND ENROLLMENT.—

(A) IN GENERAL.—In carrying out the program under paragraph (1), the Registry shall carry out informational and educational activities for purposes of recruiting individuals to serve as donors of bone marrow, and shall test and enroll with the Registry potential donors. Such information and educational activities shall include the following:

(i) * * *

(ii) Educating and providing information to individuals who are willing to serve as potential donors[, including providing updates].

* * * * * * *

(3) TRANSPLANTATION AS TREATMENT OPTION.—In addition to activities regarding recruitment, the program under paragraph (1) shall provide information to physicians, other health care professionals, and the public regarding [the availability, as a potential treatment option, of receiving a transplant of bone marrow from an unrelated donor] *transplants from unrelated donors as a treatment option and resources for identifying and evaluating other therapeutic alternatives*.

(d) PATIENT ADVOCACY; CASE MANAGEMENT.—

(1) * * *

(2) GENERAL FUNCTIONS.—The Office shall meet the following requirements:

(A) * * *

* * * * * * *

(C) In the case of such a patient, the Office shall serve as an advocate for the patient by directly providing to the patient (or family members, physicians, or other individuals acting on behalf of the patient) individualized services with respect to efficiently utilizing the system under subsection (b)(1) to conduct an ongoing search for a donor *and assist with information regarding third party payor matters*.

* * * * * * *

(F) The Office shall ensure that the following data are made available to patients:

(i) * * *

* * * * * * *

(v) Information concerning issues that patients may face after a transplant regarding continuity of care and quality of life.

[(v)**]** *(vi)* Such other information as the Registry determines to be appropriate.

* * * * * * *

(3) CASE MANAGEMENT.—

(A) * * *

(B) POSTSEARCH FUNCTIONS.—In addition to the case management services described in paragraph (1) for patients, the Office **[**may**]** *shall*, on behalf of patients who have completed the search for an unrelated donor, provide information and education on the process of receiving a transplant of bone marrow, including the posttransplant process.

* * * * * * *

(g) CONSULTATION.—The Secretary shall consult with the board of directors of the Registry and **[**the bone marrow donor program of the Department of the Navy**]** *the Department of Defense Marrow Donor Recruitment and Research Program operated by the Department of the Navy* in developing policies affecting the Registry.

(h) **[**APPLICATION.—To be eligible**]** *CONTRACTS.—*

(1) APPLICATION.—To be eligible to enter into a contract under this section, an entity shall submit to the Secretary and obtain approval of an application at such time, in such manner, and containing such information as the Secretary shall by regulation prescribe.

(2) CONSIDERATIONS.—In awarding contracts under this section, the Secretary shall give substantial weight to the continued safety of donors and patients and other factors deemed appropriate by the Secretary.

(i) ELIGIBILITY.—Entities eligible to receive a contract under this section shall **[**include**]** *be* private nonprofit entities.

* * * * * * *

[(l) ANNUAL REPORT REGARDING PRETRANSPLANT COSTS.—The Registry shall annually submit to the Secretary the data collected under subsection (b)(7) on comparisons of transplant centers re-

garding search and other costs that prior to transplantation are charged to patients by transplant centers. The data shall be submitted to the Secretary through inclusion in the annual report required in section 379A(c).]

SEC. 379A. BONE MARROW SCIENTIFIC REGISTRY.

(a) ESTABLISHMENT OF RECIPIENT REGISTRY.—The Secretary, acting through the Registry under section 379 (in this section referred to as the "Registry"), shall establish and maintain a scientific registry of information relating to patients who have been recipients of a transplant of bone marrow from a biologically unrelated donor. *The scientific registry shall participate in medical research that has the potential to improve transplant outcomes.*

* * * * * * *

(c) ANNUAL REPORT ON PATIENT OUTCOMES.—The Registry shall annually submit to the Secretary a report concerning patient outcomes with respect to each transplant center. Each such report shall use data collected and maintained by the scientific registry under subsection (a). [Each such report shall in addition include the data required in section 379(l) (relating to pretransplant costs).]

(d) PUBLICLY AVAILABLE DATA.—The scientific registry shall make relevant scientific information not containing individually identifiable information available to the public in the form of summaries and data sets to encourage medical research and to provide information to transplant programs, physicians, and patients.

[SEC. 379B. AUTHORIZATION OF APPROPRIATIONS.

[For the purpose of carrying out this part, there are authorized to be appropriated $18,000,000 for fiscal year 1999, and such sums as may be necessary for each of the fiscal years 2000 through 2003.]

SEC. 379B. BONE MARROW AND MARROW DEFINED.

For purposes of this part, the terms "bone marrow" and "marrow" include bone marrow and any other source of hematopoietic progenitor cells the acquisition or use of which is not inconsistent with Federal law.

SEC. 379C. AUTHORIZATION OF APPROPRIATIONS.

(a) IN GENERAL.—For the purpose of carrying out this part, there are authorized to be appropriated $32,000,000 for fiscal year 2004, and such sums as may be necessary for each of the fiscal years 2005 through 2008.

(b) EMERGENCY CONTINGENCY RESPONSE CAPABILITIES.—In addition to the amounts authorized to be appropriated under subsection (a), there are authorized to be appropriated such sums as may be necessary for the maintenance and expansion of emergency contingency response capabilities under section 379(b)(3).

* * * * * * *

○