

ORGAN DONATION IMPROVEMENT ACT OF 2003

FEBRUARY 13, 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. 399]

[Including cost estimate of the Congressional Budget Office]

The Committee on Energy and Commerce, to whom was referred the bill (H.R. 399) to amend the Public Health Service Act to promote organ donation, having considered the same, report favorably thereon without amendment and recommend that the bill do pass.

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PURPOSE AND SUMMARY

The purpose of H.R. 399, the Organ Donation Improvement Act of 2003, is to create new incentives for people to become organ donors and provides for studies and demonstration projects to encourage organ donation education efforts across the country.

BACKGROUND AND NEED FOR LEGISLATION

Medical advances and the generosity of organ and tissue donors enable more than 22,000 Americans per year to receive organ transplants that save or enhance their lives. Despite the self-sacrifice and charity of these donors, this is only a small proportion of the more than 76,000 Americans who are now on a waiting list, hoping to prolong their lives by finding a matching donor. Tragically, the number of patients waiting for organ transplants rose more than five times as fast as the number of transplant operations in the 1990s, according to an annual report by the United Network for Organ Sharing (UNOS). As a result, about 5,500 people die in the United States each year (or 15 patients each day) while waiting for a donated heart, liver, kidney, or other organ. It is estimated that every 16 minutes, a new name is added to this growing waiting list.

Minorities, representing approximately 25 percent of the population, comprise over 40 percent of the organ transplant waiting list. Half of the patients who die while patiently waiting for their "gift of life" are people of color.

As the demand for transplantation increases, this shortfall in donor organs for those with end-stage organ disease or organ failure will become even more pronounced. In order to narrow the gap between the supply and the increasing demand for donated organs, there must be an effort to encourage willing donors and create an environment conducive to organ donation.

H.R. 399 accomplishes this objective by permitting the Secretary of the Department of Health and Human Services (HHS) to make awards of grants or contracts to States, transplant centers, qualified organ procurement organizations, or other public or private entities for the purposes of providing for the payment of travel and subsistence expenses incurred by individuals toward making living donations of their organs. In addition, the bill orders the Secretary to carry out studies and demonstration projects for the purpose of educating the public with respect to organ donation. These grants will assist the States in carrying out organ donor awareness, public education, and outreach activities, and programs designed to increase the number of organ donors within a State, including living donors.

HEARINGS

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

COMMITTEE CONSIDERATION

On Wednesday, January 29, 2003, the Full Committee on Energy and Commerce met in open markup session and ordered H.R. 399 favorably reported to the House, without amendment, by a voice vote, a quorum being present.

COMMITTEE VOTES

There were no record votes taken in connection with ordering H.R. 399 reported. A motion by Mr. Tauzin to order H.R. 399 re-

ported to the House, without amendment, was agreed to by a voice vote.

COMMITTEE OVERSIGHT FINDING

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. 399 is to improve the rate of organ donations by providing new incentives for donations and requiring studies of organ donations.

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. 399, the “Organ Donation Improvement Act of 2003”, 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, February 10, 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. 399, the Organ Donation Improvement Act of 2003.

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. 399—Organ Donation Improvement Act of 2003

H.R. 399 would amend the Public Health Service Act to promote organ donation. The bill would authorize the appropriation of \$5 million a year in 2004 through 2008 for travel and subsistence expenses for qualifying individuals who make a living donation of

their organs. H.R. 399 would also authorize the appropriation of \$15 million in fiscal year 2004 for a program to increase public awareness of organ donation and for studies and demonstrations designed to increase the rate of organ donation. It would authorize such sums as may be necessary for this program from 2005 through 2008.

CBO estimates that implementing H.R. 399 would cost \$6 million in 2004 and a total of \$79 million from 2004 through 2008, without adjusting for inflation, and \$81 million if inflation adjustments are included, assuming appropriation of the necessary amounts. The legislation would not affect direct spending or receipts.

The estimated budgetary of H.R. 399 is shown in the following table. The table shows two alternative spending paths: one assuming no increases to account for anticipated inflation, and one with annual inflation adjustments. For purposes of this estimate, CBO assumes that outlays will follow historical spending rates for similar activities. The costs of this legislation fall within budget function 550 (health).

H.R. 399 contains no intergovernmental or private-sector mandates as defined in the Unfunded Mandates Reform Act. The bill would provide grants to states and other public and private entities for assistance to individuals who donate living organs and for educational and outreach activities.

| | By fiscal year, in millions of dollars— | | | | | |
|--|---|------|------|------|------|------|
| | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 |
| CHANGES IN SPENDING SUBJECT TO APPROPRIATION | | | | | | |
| Without Adjustments for Inflation | | | | | | |
| Estimated authorization level | 0 | 20 | 20 | 20 | 20 | 20 |
| Estimated outlays | 0 | 6 | 15 | 18 | 20 | 20 |
| Without Adjustments for Inflation | | | | | | |
| Estimated authorization level | 0 | 20 | 20 | 21 | 21 | 21 |
| Estimated outlays | 0 | 6 | 15 | 19 | 20 | 21 |

The CBO staff contact is Margaret Nowak. This estimate was 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

This section provides the short title of the bill, the “Organ Donation Improvement Act of 2003.”

Section 2. Sense of Congress

Section 2 sets out the sense of Congress with respect to organ donation and recognizes the importance of family discussions on organ donation. This section also acknowledges the generous contributions made by living organ donors, and the remarkable advances in medical technology which have made organ transplantation possible.

Section 3. Payment of travel and subsistence expenses incurred toward living organ donation

Section 3 amends section 377 of the Public Health Service Act to permit the Secretary of the Department of Health and Human Services to make awards of grants or contracts to states, transplant centers, qualified organ procurement organizations, or other public or private entities for the purpose of providing for the payment of travel and subsistence expenses incurred by individuals toward making living donations of their organs. Payments under this section may be made for expenses of a donating individual only if: (1) the state in which the donating individual resides is a different state than the state in which the intended recipient of the organ resides and (2) the annual income of the intended recipient of the organ does not exceed \$35,000.

While section 4 of H.R. 399 authorizes a grant program to the separate states to increase organ donation, which could establish their own travel and subsistence programs, section 3 program is for those donations affecting interstate commerce (hence the requirement that the recipient must reside in a state other than the residence of the living donor). The amount of qualifying expenses for which payments under such subsection are made may not exceed the amount of such expenses for which payment would have been made if such area had been the covered vicinity for the intended recipient, taking into account the costs of travel and regional differences in the costs of living. Capping qualifying expenses to that which might be incurred at a local transplant center was a solution proposed to control costs of the program. While recipients can receive a transplant from any place they desire, reimbursed expenses would be limited to the equivalent of having gone to the transplant center closest to the residence of the recipient.

Likewise, the annual income of the intended recipient of the organ was capped at \$35,000 for the section 3 program, because it was established to assist those recipients of relatively modest means who may not be in a position to make a prospective donor whole financially for lost wages and costs associated with travel.

Section 4. Public awareness; studies and demonstrations

Section 4 amends Part H of title III of the Public Health Service Act to permit the Secretary to make grants to states to carry out studies and demonstration projects for the purpose of educating the public with respect to organ donation. These grants will assist the states in carrying out organ donor awareness, public education, and outreach activities, and programs designed to increase the number of organ donors within a state, including living donors. Each state would be required to establish yearly benchmarks for improving organ donation rates in the state; develop, enhance, or expand the state's donor registry; and, report to the Secretary on an annual basis an assessment of the state's use of these grant funds.

Section 5. Effective date

The amendments made by this act take effect on the date of enactment.

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 H—ORGAN TRANSPLANTS

* * * * *

[SEC. 377. STUDY BY GENERAL ACCOUNTING OFFICE.

[(a) IN GENERAL.—The Comptroller General of the United States shall conduct a study for the purpose of determining—

[(1) the extent to which the procurement and allocation of organs have been equitable, efficient, and effective;

[(2) the problems encountered in the procurement and allocation; and

[(3) the effect of State required-request laws.

[(b) REPORT.—Not later than January 7, 1992, the Comptroller General of the United States shall complete the study required in subsection (a) and submit to the Committee on Energy and Commerce of the House of Representatives, and to the Committee on Labor and Human Resources of the Senate, a report describing the findings made as a result of the study.]

PAYMENT OF TRAVEL AND SUBSISTENCE EXPENSES INCURRED TOWARD LIVING ORGAN DONATION

SEC. 377. (a) IN GENERAL.—The Secretary may make awards of grants or contracts to States, transplant centers, qualified organ

procurement organizations under section 371, or other public or private entities for the purpose of—

(1) providing for the payment of travel and subsistence expenses incurred by individuals toward making living donations of their organs (in this section referred as “donating individuals”); and

(2) in addition, providing for the payment of such incidental nonmedical expenses that are so incurred as the Secretary determines by regulation to be appropriate.

(b) **ELIGIBILITY.**—

(1) **IN GENERAL.**—Payments under subsection (a) may be made for the qualifying expenses of a donating individual only if—

(A) the State in which the donating individual resides is a different State than the State in which the intended recipient of the organ resides; and

(B) the annual income of the intended recipient of the organ does not exceed \$35,000 (as adjusted for fiscal year 2004 and subsequent fiscal years to offset the effects of inflation occurring after the beginning of fiscal year 2003).

(2) **CERTAIN CIRCUMSTANCES.**—Subject to paragraph (1), the Secretary may in carrying out subsection (a) provide as follows:

(A) The Secretary may consider the term “donating individuals” as including individuals who in good faith incur qualifying expenses toward the intended donation of an organ but with respect to whom, for such reasons as the Secretary determines to be appropriate, no donation of the organ occurs.

(B) The Secretary may consider the term “qualifying expenses” as including the expenses of having one or more family members of donating individuals accompany the donating individuals for purposes of subsection (a) (subject to making payment for only such types of expenses as are paid for donating individuals).

(c) **LIMITATION ON AMOUNT OF PAYMENT.**—

(1) **IN GENERAL.**—With respect to the geographic area to which a donating individual travels for purposes of subsection (a), if such area is other than the covered vicinity for the intended recipient of the organ, the amount of qualifying expenses for which payments under such subsection are made may not exceed the amount of such expenses for which payment would have been made if such area had been the covered vicinity for the intended recipient, taking into account the costs of travel and regional differences in the costs of living.

(2) **COVERED VICINITY.**—For purposes of this section, the term “covered vicinity”, with respect to an intended recipient of an organ from a donating individual, means the vicinity of the nearest transplant center to the residence of the intended recipient that regularly performs transplants of that type of organ.

(d) **RELATIONSHIP TO PAYMENTS UNDER OTHER PROGRAMS.**—An award may be made under subsection (a) only if the applicant involved agrees that the award will not be expended to pay the qualifying expenses of a donating individual to the extent that payment has been made, or can reasonably be expected to be made, with respect to such expenses—

(1) under any State compensation program, under an insurance policy, or under any Federal or State health benefits program; or

(2) by an entity that provides health services on a prepaid basis.

(e) *DEFINITIONS.*—For purposes of this section:

(1) The term “covered vicinity” has the meaning given such term in subsection (c)(2).

(2) The term “donating individuals” has the meaning indicated for such term in subsection (a)(1), subject to subsection (b)(2)(A).

(3) The term “qualifying expenses” means the expenses authorized for purposes of subsection (a), subject to subsection (b)(2)(B).

(f) *AUTHORIZATION OF APPROPRIATIONS.*—For the purpose of carrying out this section, there is authorized to be appropriated \$5,000,000 for each of the fiscal years 2004 through 2008.

PUBLIC AWARENESS; STUDIES AND DEMONSTRATIONS

SEC. 377A. (a) PUBLIC AWARENESS.—The Secretary shall (directly or through grants or contracts) carry out a program to educate the public with respect to organ donation, including the need to provide for an adequate rate of such donations.

(b) *STUDIES AND DEMONSTRATIONS.*—The Secretary may make grants to public and nonprofit private entities for the purpose of carrying out studies and demonstration projects with respect to providing for an adequate rate of organ donation.

(c) *GRANTS TO STATES.*—The Secretary may make grants to States for the purpose of assisting States in carrying out organ donor awareness, public education and outreach activities and programs designed to increase the number of organ donors within the State, including living donors. To be eligible, each State shall—

(1) submit an application to the Department in the form prescribed;

(2) establish yearly benchmarks for improvement in organ donation rates in the State;

(3) develop, enhance, or expand a State donor registry, which shall be available to hospitals, organ procurement organizations, tissue banks, eye banks, and other States upon a search request; and

(4) report to the Secretary on an annual basis a description and assessment of the State’s use of these grant funds, accompanied by an assessment of initiatives for potential replication in other States.

Funds may be used by the State or in partnership with other public agencies or private sector institutions for education and awareness efforts, information dissemination, activities pertaining to the State donor registry, and other innovative donation specific initiatives, including living donation.

(d) *ANNUAL REPORT TO CONGRESS.*—The Secretary shall annually submit to the Congress a report on the activities carried out under this section, including provisions describing the extent to which the activities have affected the rate of organ donation.

(e) *AUTHORIZATION OF APPROPRIATIONS.*—

(1) *IN GENERAL.*—For the purpose of carrying out this section, there are authorized to be appropriated \$15,000,000 for fiscal year 2004, and such sums as may be necessary for each of the fiscal years 2005 through 2008. Such authorization of appropriations is in addition to any other authorizations of appropriations that are available for such purpose.

(2) *STUDIES AND DEMONSTRATIONS.*—Of the amounts appropriated under paragraph (1) for a fiscal year, the Secretary may not obligate more than \$2,000,000 for carrying out subsection (b).

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