

# ORGAN DONATION IMPROVEMENT ACT OF 2001

MARCH 6, 2001.—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. 624]

[Including cost estimate of the Congressional Budget Office]

The Committee on Energy and Commerce, to whom was referred the bill (H.R. 624) 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

H.R. 624, the Organ Donation Improvement Act of 2001, is solely focused on creating new incentives for people to become organ donors and provides for studies and demonstration projects to encourage organ donation education efforts across the country. The bill accomplishes this objective by permitting 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. 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.

#### BACKGROUND AND NEED FOR LEGISLATION

In 1999, 21,715 Americans received the “gift of life” through transplantation surgery made possible by the generosity of organ and tissue donors. Despite the self-sacrifice and charity of these donors, this is only a small proportion of the more than 70,000 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). Nearly 5,000 patients each year (or 13 patients each day), die 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, and 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.

In the last two Congresses, the Committee has held three hearings on solid organ transplantation. Among the issues raised in these hearings included the need for increasing organ donation through initiatives like those included in H.R. 624. The Committee found that there are willing donors who would like to save the life of another American, but often find themselves in financial circumstances that would make donation of a life-saving organ even more of a hardship. Travel expenses, lengthy hospital stays, and time away from one’s job can all create financial and emotional strains on donor families. These hardships discourage organ donation.

The Committee also found that our Nation’s organ donation education efforts need to be strengthened in order to increase the number of donors, and encourage family members to discuss organ and tissue donation at appropriate times. In addition, States need additional funds in order to bolster their organ donor awareness, public education, and outreach activities.

Obstacles to organ donation create disincentives for willing donors and ultimately increase waiting times and waiting lists for patients with end-stage organ disease and organ failure.

The organ donation provisions contained in H.R. 624 are the same provisions that were the subject of markup in Subcommittee (September 30, 1999), markup in Full Committee (October 13, 1999), and House passage (April 4, 2000 by a vote of 275–147) of H.R. 2418, the Organ Procurement and Transplantation Network Amendments of 2000. The votes against H.R. 2418 were focused on the provisions relating to Secretarial authority over the allocation process, which have not been included in H.R. 624.

#### HEARINGS

The Committee on Energy and Commerce has not held hearings on this bill.

#### COMMITTEE CONSIDERATION

On February 28, 2001, the Subcommittee on Health was discharged from the further consideration of H.R. 624. On February 28, 2001, the Full Committee met in open markup session and approved H.R. 624, without amendment, by a voice vote.

#### 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. 624 reported.

#### COMMITTEE OVERSIGHT FINDINGS

Pursuant to clause 3(c)(1) of rule XIII of the Rules of the House of Representatives, the Committee has held no oversight hearing.

#### STATEMENT OF GENERAL PERFORMANCE GOALS AND OBJECTIVES

This legislation will 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. 624, the Organ Donation Improvement Act of 2001, 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, March 6, 2001.*

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. 624, the Organ Donation Improvement Act of 2001.

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

Sincerely,

BARRY B. ANDERSON  
(For Dan L. Crippen, Director).

Enclosure.

*H.R. 624—Organ Donation Improvement Act of 2001*

H.R. 624 would amend the Public Health Service Act to promote organ donation. The bill, as modified, would authorize appropriation of \$5 million a year in 2002 through 2006 for travel and subsistence expenses for qualifying individuals making living donation of their organs. H.R. 624, as modified, would also authorize appropriation of \$15 million in fiscal year 2002 for a program to educate the public and for studies and demonstrations designed to increase the rate of organ donation. It would authorize such sums as may be necessary for these activities from 2003 through 2006.

Assuming appropriations of the necessary amounts, CBO estimates that implementing H.R. 624 would cost \$6 million in 2002 and a total of \$78 million from 2002 through 2006, without adjusting for inflation, and \$80 million if inflation adjustments are included. The legislation would not affect direct spending or receipts; therefore, pay-as-you-go procedures would not apply.

The estimated budgetary impact of H.R. 624 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. 624 contains no private-sector or intergovernmental 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—					
	2001	2002	2003	2004	2005	2006
CHANGES IN SPENDING SUBJECT TO APPROPRIATION						
Without Adjustments for Inflation						
Estimated Authorization Level .....	0	20	20	20	20	20
Estimate Outlays .....	0	6	15	18	20	20
With Adjustments for Inflation						
Estimated Authorization Level .....	0	20	20	21	21	21
Estimate Outlays .....	0	6	15	19	20	21

The CBO staff contact is Mara Krause. 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 2001.”

##### *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. 624 authorizes a grant program to the separate States to increase organ donation, which could establish their own travel and subsistence programs, the 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 the 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**

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# TITLE III—GENERAL POWERS AND DUTIES OF PUBLIC HEALTH SERVICE

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## PART H—ORGAN TRANSPLANTS

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### [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 2001 and subsequent fiscal years to offset the effects of inflation occurring after the beginning of fiscal year 2000).*

*(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 2000 through 2005.*

*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, 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 organ 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 2000, and such sums as may be necessary for each of the fiscal years 2001 through 2005. Such authorization of appropriations is in addition to any other authorizations of appropriations that is 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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