

Date of Hearing: April 26, 2022

ASSEMBLY COMMITTEE ON HEALTH
Jim Wood, Chair
AB 2504 (Kalra) – As Amended April 19, 2022

SUBJECT: Living Organ Donor Reimbursement Act.

SUMMARY: Establishes the Living Organ Donor Reimbursement (LODR) Program within the Department of Health Care Services (DHCS) to reduce financial barriers for living organ donors of specified organs by providing reimbursement of up to \$10,000 per organ donation for qualified donation expenses. Sunsets the provisions of this bill on January 1, 2027. Specifically, **this bill:**

- 1) Establishes the LODR Program for the purpose of reducing financial barriers for living organ donors by providing reimbursement for the costs associated with organ donation.
- 2) Requires DHCS to administer the program in accordance with this bill.
- 3) Defines, for purposes of this bill, the following:
 - a) A “living organ donor” as an individual who has donated all or part of an organ and is not deceased at the time of donation;
 - b) An “organ” to mean all or part of an individual’s liver, kidney, pancreas, intestine, lung, or bone marrow; and,
 - c) “Qualified donation expenses” to mean any of the following expenses that are directly related to the organ donation and were not, or will not, be reimbursed by any other source:
 - i) Travel and lodging expenses;
 - ii) Lost wages during the organ donation and recovery period;
 - iii) Child care and elder care costs during the organ donation and recovery period; and,
 - iv) Living organ donor-incurred copayments and deductibles for prescription and over-the-counter medications needed as a result of the donation.
- 4) Permits a living organ donor to submit an application to DHCS for reimbursement of qualified donation expenses, not to exceed \$10,000 per organ donation.
- 5) Requires DHCS to review applications in the order they are received.
- 6) Requires DHCS, if an application or claim for reimbursement will be rejected or deemed incomplete, to notify the applicant and provide the applicant an opportunity to correct or complete the application.
- 7) Prohibits DHCS from awarding a living organ donor more than \$10,000 in reimbursement costs per organ donation.
- 8) Requires DHCS, upon approval of an application, to notify the Controller of award amounts for reimbursement from the LODR Fund.

- 9) Requires DHCS to establish a process to facilitate the submission of applications pursuant to this bill.
- 10) Establishes in the State Treasury the LODR Fund, and requires moneys in the fund, upon appropriation by the Legislature, to be allocated by the Controller to living organ donors whose applications are approved by DHCS.
- 11) Permits the Controller to also accept donations from private entities for deposit in the LODR Fund, and requires moneys in the Fund that have been donated to be continuously appropriated for allocation to living organ donors whose applications are approved by DHCS.
- 12) Permits gifts received pursuant to this bill to be accepted without approval of the Department of Finance.
- 13) Requires that no more than a reasonable and necessary amount of the funds that are made available for purposes of this bill are for administrative costs in order to maximize the availability of funds for qualified donation expenses by living organ donors and to increase the rate of donation by qualified living donors.
- 14) Requires DHCS to furnish a report to the Legislature that includes all of the following:
 - a) The number of individuals receiving reimbursement for qualified donation expenses;
 - b) The mean, median, and overall dollar amounts reimbursed for qualified donation expenses as a result of this bill, overall and by type of organ donation;
 - c) The types of organs donated by the living organ donors;
 - d) The gender, race, and age of the living organ donors and the recipients;
 - e) The number of individuals on the donor waiting list prior to the enactment of this bill, and the number following the enactment of this bill; and,
 - f) The number of living donors in the year prior to the enactment of this bill, and each year following the enactment of this bill.
- 15) Requires the report required to be posted on the DHCS internet website and to be provided to the appropriate policy and fiscal committees of the Legislature on or before January 1, 2026.
- 16) Sunsets this bill January 1, 2027.
- 17) Makes a legislative finding and declaration that the LODR Program established by this bill serves the public purpose of reducing financial barriers for living organ donors by providing reimbursement for the costs associated with organ donation, and does not constitute a gift of public funds within the meaning of a specified provision of the California Constitution.

EXISTING LAW:

- 1) Makes it unlawful, under the federal National Organ Transplant Act, for any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in human transplantation if the transfer affects interstate commerce.

- 2) Defines "human organ" to mean the human (including fetal) kidney, liver, heart, lung, pancreas, bone marrow, cornea, eye, bone, and skin or any subpart thereof and any other human organ (or any subpart thereof, including that derived from a fetus) specified by the federal Secretary of the Department of Health and Human Services (DHHS) by regulation.
- 3) Exempts from the definition of "valuable consideration" the reasonable payments associated with the removal, transportation, implantation, processing, preservation, quality control, and storage of a human organ or the expenses of travel, housing, and lost wages incurred by the donor of a human organ in connection with the donation of the organ.
- 4) Establishes penalties for violation of the above described provisions of not not more than \$50,000 or imprisonment of not more than five years, or both.
- 5) Permits, under federal law, a federal employee to use up to seven days of leave to serve as a bone-marrow donor and up to 30 days of leave to serve as an organ donor.
- 6) Requires, under state law known as the Michelle Maykin Memorial Donation Protection Act, a private employer to permit an employee to take a leave of absence with pay, not exceeding 30 business days in a one-year period, for the purpose of organ donation.
- 7) Requires, under state law, a private or public employer to grant an employee an additional unpaid leave of absence, not exceeding 30 business days in a one-year period, for the purpose of organ donation. Requires a public employee to first exhaust all available sick leave before taking that unpaid leave.
- 8) Requires, pursuant to state regulation, health plans that offer coverage in the individual or small group market to cover organ donation services for actual or potential living donors, in addition to transplant services of organs, tissue, or bone marrow required under the Knox-Keene Health Care Service Plan Act of 1975, as follows:
 - a) Coverage for donation-related services for a living donor, or an individual identified by the plan as a potential donor, whether or not the donor is an enrollee. Requires services to be directly related to a covered transplant for the enrollee, which include services for harvesting the organ, tissue, or bone marrow and for treatment of complications, pursuant to the following guidelines:
 - i) Services are directly related to a covered transplant service for an enrollee or are required for evaluating potential donors, harvesting the organ, bone marrow, or stem cells, or treating complications resulting from the evaluation or donation, but not including blood transfusions or blood products;
 - ii) Donor receives covered services no later than 90 days following the harvest or evaluation service;
 - iii) Donor receives services inside the United States, with the exception that geographic limitations do not apply to treatment of stem cell harvesting;
 - iv) Donor receives written authorization for evaluation and harvesting services;
 - v) For services to treat complications, the donor either receives non-emergency services after written authorization, or receives emergency services the plan would have covered if the enrollee had received them; and,
 - vi) In the event the enrollee's plan membership terminates after the donation or harvest, but before the expiration of the 90 day time limit for services to treat complications,

the plan shall continue to pay for medically necessary services for donor for 90 days following the harvest or evaluation service.

FISCAL EFFECT: Unknown. This bill has not been analyzed by a fiscal Committee.

COMMENTS:

- 1) **PURPOSE OF THIS BILL.** According to the author, living organ donors selflessly make the choice to give the gift of life. In 2021, there were 2,777 kidney transplants performed in California and 25% of those transplants were from living organ donors. The author notes that, while health insurance typically covers all medical costs associated with the transplant, it does not cover out-of-pocket expenses, such as travel, lodging, childcare, and medications. The author states that this bill would be the first in the country to establish the LODR Program which will allow organ donors to recoup any out-of-pocket expenses for up to \$10,000. This reimbursement will reduce financial barriers for organ donors and encourage more people to become living organ donors and save a life.

- 2) **BACKGROUND.** There are long-standing waiting lists for organ donations in California and nationally. In California, according to the Organ Procurement and Transplantation Network, as of April 7, 2022 there were 21,740 Californians awaiting a donor, comprised of 13,460 (62.6%) males and 8,280 (38%) females. The ethnicity of those who are on the donor waiting list are Hispanic/Latino (9,699 or 44.6%), followed by White (4,815 or 22.1%), Asian (4,418 or 20.3%), Black (2,161 or 9.9%), Pacific Islander (319 or 1.5%), American Indian/Alaska Native (101 or .46%) and multiracial (227 or 1%). The most common organ in need of donation is the kidney, comprising 86.6% of the Californians on the wait list. Of the 18,831 Californians in need of a kidney donation, 4,176 or 22.1% of Californians have had a wait time of three to five years, and 4,209 or 22.3% have had a wait time of five or more years. The number of Californians on the wait list as of April 4, 2022 by type of organ is shown in the chart below:

All Organs	Kidney	Liver	Pancreas	Kidney / Pancreas	Heart	Lung	Heart / Lung	Intestine	Abdominal Wall
20,584	18,057	2,150	62	220	268	144	4	34	1

In California, according to the Organ Procurement and Transplantation Network, most donated organs are from deceased donors. In 2021, there were 608 living donors in California, as compared to 1,268 deceased donations.

Federal law, enacted in 2004 (Public Law 108-216, the Organ Donation and Recovery Improvement Act) authorized the federal DHHS Secretary to award grants to states, transplant centers, qualified organ procurement organizations, or other public or private entities for the purpose of: a) providing for the reimbursement of travel and subsistence expenses incurred by individuals toward making living donations of their organs (referred to as ‘donating individuals’); and, b) providing for the reimbursement of such incidental nonmedical expenses that are so incurred as the Secretary determines by regulation to be appropriate.

- 3) **SUPPORT.** This bill is sponsored by the American Kidney Fund (AKF), which writes that while most transplanted organs are from deceased donors, patients may also receive organs

from living donors. Living donation offers an alternative for individuals awaiting transplantation and increases the existing organ supply. Over 6,000 living-donor transplants were performed last year in the United States, and 609 of those were kidney transplants from living organ donors in California. AKF writes that kidneys are the most common organ transplanted from living donors, followed by liver and lung. Both living and deceased donation offer hope to over 106,000 people nationwide waiting for an organ transplant right now—including more than 92,000 who are waiting for a kidney transplant. In addition to transforming the life of the kidney patient, a transplant is a boon to society. The cost of a transplant is lower than long-term kidney dialysis, and it gives the transplant recipient a greater ability to remain in or return to the workforce.

AKF argues this bill allows a living organ donor to recoup some or all the expenses they incur for the costs associated with organ donation up to \$10,000. The transplant recipient's health insurance typically pays all surgery costs for the living donor but does not necessarily reimburse out-of-pocket expenses such as travel, lodging, childcare, elder care, and some medications that may be needed during recovery. This bill would help lessen this potential financial obstacle for living donors. AKF concludes that it believes that providing incentives and removing financial burdens for living donors can lead to an increase in organ donations, and ultimately save lives.

- 4) **RELATED LEGISLATION.** AB 2275 (Low) requires a county coroner to have a licensed forensic pathologist present at the recovery of a donated organ in order to restrict recovery of a donated part. Makes informing the next of kin and asking whether the deceased was a donor the responsibility of the organ procurement organization (OPO), rather than the coroner, and requires a coroner to assist an OPO in the search for a person authorized to make an anatomical gift. AB 2275 is pending in the Assembly Appropriations Committee.
- 5) **PREVIOUS LEGISLATION.**
 - a) AB 1223 (Arambula), Chapter 316, Statutes of 2019, requires a private or public employer to grant an employee an additional unpaid leave of absence, not exceeding 30 business days in a one-year period, for the purpose of organ donation, provided that in the case of a public employee, they have exhausted all sick leave, and prohibits life, long-term care or disability insurance policies from discriminating against an organ donor.
 - b) SB 1304 (DeSaulnier), Chapter 646, Statutes of 2010, requires employers to provide paid leave for employees who volunteer to donate bone marrow or organ tissue, as well as prohibits employer discrimination against any employee who utilizes this leave.
 - c) AB 1825 (Nakano) Chapter 869, Statutes of 2002 requires the appointing power of state agencies to grant up to a 30-day leave of absence with pay to employees who have exhausted all available sick leave and who are organ donors, imposes the same employee leave requirements on the Trustees of the California State University, and would allow the Regents of the University of California to adopt, by resolution, the same employee leave requirements.
- 6) **POLICY QUESTION: SHOULD REIMBURSEMENT FOR THESE EXPENSES BE A GENERAL FUND RESPONSIBILITY?** Federal law authorizes the awarding of grants to States, transplant centers, qualified organ procurement organizations, or other public or private entities for the purpose of: a) providing for the reimbursement of travel and

subsistence expenses incurred by individuals toward making living donations of their organs (referred to as ‘donating individuals’); and, b) providing for the reimbursement of such incidental nonmedical expenses that are so incurred as the DHHS Secretary determines by regulation to be appropriate. It is unclear if actual grants have been awarded or in what dollar amounts. The premise of this bill is that providing General Fund (GF) for qualified donation expenses will result in an increase in donations and offset state Medi-Cal costs. There is currently no GF support for this purpose now, and it is unclear to what extent these costs are reimbursed today by private foundation and philanthropy versus a cost borne exclusively by the individual donors. Should this bill include language that makes its implementation contingent upon private contributions to offset a portion of the donation-related expenses of living donors?

REGISTERED SUPPORT / OPPOSITION:**Support**

American Kidney Fund
Be The Match/National Marrow Donor Program
California Dialysis Council
Chronic Disease Coalition
Dialysis Patient Citizens

Opposition

None on file.

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