

Invited Article

Need for Legislations in India to Safeguard Living Donors

Jaya Jairam

MOHAN Foundation, India



Ms. Jaya jairam
Project Director
MOHAN Foundation
Mumbai

Addressing Organ Shortages: The Role of Living Donors

For individuals with organ failure, transplantation offers a vital lifeline, significantly improving quality of life and survival. However, organ shortages, particularly kidney, remain a critical challenge globally, and India is no exception. Despite advancements in medical technology, the demand for organs far exceeds the availability, leading to prolonged waiting periods, that

often result in loss of lives.

The Indian Scenario: Heavy reliance on Living Donors

India faces an acute organ shortage, with approximately 500,000 people on the national waiting list. In 2023, only 1,099 deceased donors contributed to 2,935 transplants. Due to this shortfall, the transplant program has become largely dependent on living donors, accounting for 84% of the 18,378 transplants performed. Specifically, living donors facilitated over 88% of kidney transplants and 81% of liver transplants in the country.

While their contribution is indispensable, living donors face numerous challenges, including financial strain, inadequate workplace protections and insufficient post-donation support. Without a robust legal framework to address these issues, the burden on living donors continues to intensify.

Financial Neutrality and Support for Living Donors

One key area of concern is the lack of **financial neutrality**, a principle distinct from financial incentives. Financial neutrality ensures that donors do not face financial loss or hardship due to their altruistic act. Unfortunately, in India, donors often bear substantial out-of-pocket expenses, including medical bills, lost wages, and logistical costs. This not only creates a disincentive for potential donors but also perpetuates inequity in the system.

The importance of donor safeguards cannot be overstated. Protecting donors through measures such as comprehensive health monitoring, legal protections, and removal of financial and logistical barriers is critical to sustaining living donation.

Non-financial incentives, such as recognition, priority on deceased organ waiting lists, and long-term health coverage, can offer comfort, protection, and a reassuring sense of being valued and cared for by the society at large.

Learnings from Other Countries

a. Israel's successful Legislation

Countries like Israel offer valuable lessons in the creation of supportive legislative frameworks for living donors. The Israeli donor support system, implemented in 2008, has proven to be a successful and uncontroversial approach to expanding living

donation programs. Since its introduction, Israel's living donation rates have quadrupled, thanks to the creation of a structured and supportive environment for donors. These programs not only save thousands of lives but also help governments save billions of dollars annually by reducing reliance on costly dialysis treatments.

b. Legislative Measures in the US: Awaiting Congressional Approval

In the United States, several legislative initiatives have been introduced by several kidney health and transplant advocates, to protect and encourage living donors:

1. Living Donor Protection Act (H.R. 2923 / S.1384):

This bipartisan bill seeks to:

- Prohibit life, disability, and long-term care insurance companies from discriminating against living donors by denying coverage or charging higher premiums.
- Amend the Family and Medical Leave Act (FMLA) to include living organ donation as a qualifying event, ensuring job security during recovery.
- Update public educational materials to address misconceptions about living donation.

States like New York have already implemented similar laws, setting a precedent for nationwide protections. The act responds to findings, such as a 2007 study revealing that up to 11% of living donors struggle to obtain or afford insurance post-donation.

2. Honor Our Living Donors Act (H.R. 6020):

Introduced in October 2023, this bill seeks to amend the National Living Donor Assistance Center's (NLDAC) financial eligibility criteria. Currently, assistance is determined by the recipient's income, which can place undue financial burdens on donors. The bill proposes basing eligibility solely on the donor's income, covering expenses such as travel and lodging, lost wages, dependent care. This change aims to remove financial barriers and make living donation more accessible.

3. Living Organ Donor Tax Credit Act (H.R. 6171):

This bill introduced in Feb 2023, would offer a refundable tax credit of up to \$5,000 for donors' out-of-pocket expenses, including medical costs, travel, and lost wages, thus easing the financial impact of donation.

These measures aim to eliminate financial and logistical barriers, encouraging more individuals to step forward as living donors.

**The letters "H.R." and "S." signify the bill originated in the "House of Representatives" and the "Senate", respectively, followed by a number that it retains throughout all its parliamentary stages.*



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Legislative Gaps in India: An Urgent Call to Action

Unlike the U.S., India significantly lacks comprehensive policies to support living donors. As a result, donors here often encounter:

- **Inadequate health cover:** Refusal to enhance cover under a pre-existing insurance policy.
- **Insurance Discrimination:** Donors frequently face denial of health and life insurance post-donation.
- **Financial burden:** Donors have to bear substantial out-of-pocket medical expenses with nil or minimal financial assistance.
- **Lack of Workplace protections:** There is limited or no job security or paid leave during recovery period.
- **Misaligned funding criteria:** The cost of donation surgery is typically linked to the recipient's health insurance coverage rather than the donor's financial situation, creating inequity and undue dependence on recipient.
- **Unreimbursed Travel and accommodation costs:** This adds to their financial stress.

With the country's rising prevalence of lifestyle diseases such as diabetes, hypertension, and others, the need for organs for transplantation is expected to increase significantly, in parallel.

Recent discussions, such as that at NOTTO (National Organ and Tissue Transplant Organisation), India's apex body for organ donation and transplantation's 'Chintan Shivir' in New Delhi, in addressing the critical issue of lack of insurance coverage for living donors, is encouraging, and offers hope and much needed attention.

Corresponding Author: Dr. Sunil Shroff,
MOHAN Foundation, Chennai, Tamil Nadu, India
Email: shroff@mohanfoundation.org

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Key Legislative Priorities for India:

- 1. Insurance Protections:** Enact laws to prohibit discrimination against living organ donors by life, health, and disability insurance providers, ensuring equitable access to insurance coverage.
- 2. Priority listing on waiting list:** Establish policies that grant living organ donors priority access to organ transplants if they ever require one in the future, across all Indian states.
- 3. Job Security and Paid Leave:** Implement robust workplace protections for living organ donors, including guaranteed job security and provision for paid leave during the recovery period, ensuring their altruistic donation is met with tangible support.
- 4. Financial Aid Programs:** Develop government-sponsored financial aid programs to cover medical, travel, accommodation, and other incidental expenses incurred by living organ donors, alleviating the economic burden of donation.

Conclusion: A Roadmap for Change

India's reliance on living donors to address its organ shortage crisis demands urgent action. Implementing a legislative framework to protect living donors is not only an ethical obligation but also a practical necessity to sustain the organ transplant ecosystem. By learning from international best practices and tailoring them to the Indian context, the country can ensure that living donors are supported, valued, and empowered to save lives.

Such measures would not only encourage more individuals to donate but also foster a culture of organ donation built on respect, care, and systemic support.

References

- <https://livingdonor.kidneyfund.org/>
- NOTTO Annual Report 2023
- <https://www.kfwny.org/post/ny-state-rated-b-in-living-donor-protections>
- <https://www.kfwny.org/post/living-donor-protection-act-waiting>
- [https://www.kidney.org/news-stories/advocacy/expanding-living-donation-understanding-key-legislation#:~:text=The%20Living%20Donor%20Protection%20Act%20\(H.R.&text=The%20bill%20also%20seeks%20to,fear%20of%20losing%20their%20employment](https://www.kidney.org/news-stories/advocacy/expanding-living-donation-understanding-key-legislation#:~:text=The%20Living%20Donor%20Protection%20Act%20(H.R.&text=The%20bill%20also%20seeks%20to,fear%20of%20losing%20their%20employment)
- <https://www.cato.org/regulation/summer-2022/emulate-israels-program-covering-donors-expenses>

