

# INDIAN TRANSPLANT NEWSLETTER

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MULTI ORGAN HARVESTING AID NETWORK

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## Editorial Desk

### Five States Leading Deceased Donation and Transplantation in India

India's deceased organ donation program has seen significant success primarily in five states - Tamil Nadu, Karnataka, Telangana, Maharashtra, and Gujarat. Over the past three years, each of these states has consistently recorded more than 100 donations annually. In 2024 alone, they collectively contributed 909 deceased donations, accounting for nearly 75% of the country's total donor numbers.

Tamil Nadu led the efforts with a record-breaking 268 donations, marking an all-time high. Although the state experienced a temporary decline in numbers over the past few years, it has now regained its top position. A key factor in this resurgence has been the increased participation of government medical colleges, with a significant number of institutions contributing to the program. Additionally, a policy implemented by the state government to honour deceased donors by the district administration has significantly contributed to enhancing public engagement and awareness.



State honors for organ donors in Tamil Nadu - A top government official (IAS) from the Thiruvannamalai District carries a wreath during the last rites of an organ donor.

Since the inception of the deceased donation program, these five states from southern and western India have consistently advanced, while other regions have struggled to maintain momentum. This trend extends to eye donations as well, where these states continue to lead the country.

States with highest number of deceased donations			
States / Year	2022	2023	2024
Tamil Nadu	156	178	268
Telangana	194	200	188
Maharashtra	105	148	172
Karnataka	151	178	162
Gujarat	148	146	119

#### India - 2024 States with highest deceased organ donation



Source :  
<https://www.notto.mohfw.gov.in/>  
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## First Robotic Double Lung Transplant Marks a New Era in Transplantation

October 22, 2024, marked a new era in transplantation when the surgical team at NYU Langone Health accomplished a major milestone, by performing a completely robotic 'double lung transplant' on Cheryl Mehrkar, 57.

The team led by Lead surgeon Dr. Stephanie Chang used the da Vinci Xi robotic system, a modern tool meant for minimally invasive operations. The system mimics a surgeon's hand motions across tiny incisions using a 3D high-definition camera and precision instruments. Although single lung transplants have long been performed using it, this is the first time it has been used in a double lung operation.

"Double lung transplants are more complicated since most patients need both lungs; thus, we needed to simplify the procedure to ensure efficiency without compromising the donated organs," Dr. Chang said. In addition, Dr. Chang expressed hope about the outcomes and expected Mehrkar to resume her beloved hobbies, so ushering a hopeful new chapter in her life.

This milestone shows how robotic systems could revolutionize organ transplantation, opening the door to more exact, quick, and minimally invasive treatments in the future.

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## A Kidney Donor in the Past, Now a Recipient of Genetically Modified Pig Kidney

Towana Looney, 53, is free from dialysis and in better health following a gene-edited pig kidney transplant last month by NYU Langone Health surgeons. The operation represents the most recent encouraging development in a newly developed surgical technique suggested as the fix for the organ shortage. Looney gave one of her kidneys to her mother in 1999. But she developed a disorder that finally resulted in chronic kidney disease when she became pregnant with her second child in 2002. Looney started dialysis late in 2016. She was highly sensitized; thus, she couldn't find a good match. One further choice was a genetically modified pig kidney.

Looney's fresh kidney came from United Therapeutics' subsidiary, Revivicor Inc - the company modified the DNA of the pig. The kidney was engineered with 10 genetic edits to optimize compatibility with the human body. On January 25, 2025 with her new kidney completing 61 days and still counting, Towana Looney became the first longest-living recipient of a xenotransplant.

**To cite :** Sharma P, Suriyamoorthi S. A Kidney Donor in the Past, Now a Recipient of Genetically Modified Pig Kidney. In the news. Indian Transplant Newsletter. 2024 Oct-Dec; 23(4):p2. DOI: 10.64384/ITN.2024.063

## US Implements Policy Change: Allows Organ Transplants from HIV-Positive Donors

New guidelines allowing HIV-positive people to get kidney or liver transplants from HIV-positive donors have been published by US health officials. This new regulation removes unnecessary barriers to kidney and liver transplants, expanding the organ donor pool and improving transplant outcomes for HIV-positive individuals. Such transplants were previously limited to research studies.

Studies have confirmed the desirable outcome of this approach. According to a recent study written up in the New England Journal of Medicine (<https://www.nejm.org/doi/full/10.1056/NEJMoa2403733>), recipients had low organ rejection rates and comparable survival rates. This evolution expands on past achievements including: In 2010, South African surgeons provided the first evidence demonstrating using HIV-positive donor organs for those living with HIV was safe. But the practice wasn't allowed in the United States until 2013 when the government lifted a ban and approved research initiatives.

The studies first involved contributions from deceased donors with HIV. Then in 2019, a Baltimore team at Johns Hopkins University carried out the first kidney transplant from a living donor with HIV to an HIV-positive recipient. The US has conducted almost 500 successful transplants of kidneys and livers from HIV-positive donors.

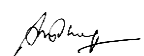
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I, Sunil Shroff, hereby declare that the particulars given above are true to the best of my knowledge and belief.

Sd/-  
Sunil Shroff



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## Impact of State Honour' Initiative: Tamil Nadu Registers All-time Increase in Organ Donations

Tamil Nadu has set a new record and has reported 268 deceased organ donations in 2024, against 178 in 2023, leading to 1,500 deceased donor organ transplants in a year. The state retrieved 863 solid organs and 637 tissues, the highest numbers since the inception of state's deceased donor transplant program in 2008.

The increase has been attributed to the Tamil Nadu government's State Honour initiative, introduced in September 2023, to honour deceased organ donors at their funerals. 326 of them have received State Honours; inspiring a total of 11,547 voluntary new registrations in 2024, bringing the total to 19,097 in just 2 years.

By offering continuous medical education programs and supporting grief-stricken families, the Tamil Nadu Transplant Authority (TRANSTAN) has helped in achieving this rise, said Dr N Gopalakrishnan, Member-Secretary, TRANSTAN. He also added, that the "Honour Walk," first initiated by the Rajiv Gandhi Government General Hospital (RGGGH) in Chennai, and currently carried out by several other government medical facilities is responsible for the rise in numbers. This is also one of the factors motivating many individuals to donate their organs.

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## Kota Becomes the First City to Place Plaques Outside the Homes of Corneal Donor Families

Kota became the first city in the country, to place a plaque outside the houses of corneal donor families, which has "I am proud to be an eye-donating family" scripted in golden letters.

This interesting awareness campaign was started by the Shine India Foundation, Rajasthan which has been continuously working for eye donation awareness, rights of the visually challenged, awareness about organ donation, body donation and skin donation in Hadoti division for the last 13 years.

Dr. Sangeeta Gaur, the founder secretary of the organization explained that the plaque is meant to inspire anyone visiting the house to consider eye donation. At the same time, it serves as a source of pride for the family, reminding them of their meaningful contribution.

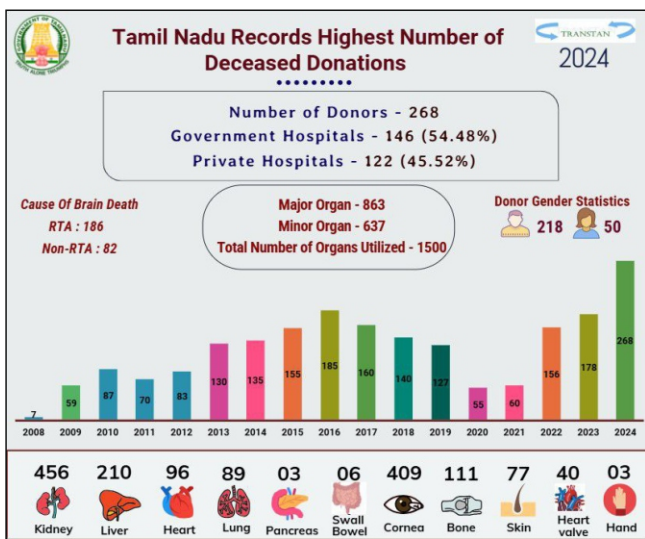
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## NOTTO's New Move: Centralized Cornea Waitlist Soon

Organ waiting lists - heart, liver, kidney - are available centrally on the National Organ and Tissue Transplant Organization's (NOTTO) website (<https://www.notto.mohfw.gov.in/>); no such list exists for cornea as of yet. Eventually, a centralised platform will show the list of Indian patients awaiting a cornea transplant. In a recent move, NOTTO has written to all the states/UTs to direct the registered hospitals as well as eye banks for sharing the data such as list of patients waiting for cornea transplant, number of cornea donation and transplantation as well as number of corneas stored or utilised.

Professor Dr. Namrata Sharma, Professor of Ophthalmology, AIIMS and Vice President, Eye Bank Association of India (EBAI) spoke about the widening gap between the demand and supply of cornea. She stated that the required demand for corneas stands at around two lakh per year to treat patients suffering from blindness. In 2023-24 alone, a little over 49,315 corneas were retrieved, but only 27,394 were suitable for transplant. Further, she laid emphasis on the fact that more details on cornea collection and additional use, would allow legislators ensure equitable access and optimum use of tissue that was obtained. For eye banks to renew their operational license, NOTTO has made it compulsory for such institutions to procure a minimum of 100 corneas every year.

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## Odisha - An Emerging State's Experience with Deceased Organ Donation



**Dr. Bramhadatta Pattnaik**  
Associate Professor & HOD  
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### **AIIMS Bhubaneswar has recently initiated deceased organ donation program. Tell us about it?**

AIIMS Bhubaneswar achieved a landmark milestone by performing its first deceased organ donation on February 23, 2024. This was followed by two more successful organ donations in July 2024 and October 2024, reflecting the institution's evolving intent towards this noble work.

The journey began with the start of living kidney transplants on August 30, 2022. To promote awareness, the hospital conducted several public education campaigns. A dedicated transplant coordinator was appointed to streamline the organ donation process. Brainstem Death Certifying committee was formed with the guidance from SOTTO Odisha.

The first donation involved a 14-year-old female admitted on February 15, 2024, with loss of consciousness. She was a known case of CKD and hypertension, undergoing maintenance dialysis. A multidisciplinary team, with the support from AIIMS administration and SOTTO Odisha, confirmed brainstem death on February 22, 2024. While approached, her family courageously consented for organ donation. Her liver was retrieved by the AIIMS Bhubaneswar team in collaboration with ILBS, New Delhi and transported to ILBS for transplantation.

Subsequent organ donations in July 2024 and October 2024 further established AIIMS Bhubaneswar as a key player in organ transplantation.

### **Which all organs have been retrieved in the donations? Did AIIMS Bhubaneswar utilize any of the donated organs?**

We successfully retrieved livers and kidneys during our organ donation efforts. Additionally, we independently retrieved liver from a 2-year-old pediatric BSD donor, and the liver was transported to ILBS, New Delhi. On July 7, 2024, we conducted our second cadaveric kidney transplant as part of our ongoing organ donation efforts. To date, we have performed a total of four deceased donor kidney transplants.

### **Is AIIMS Bhubaneswar also the first government hospital in Odisha to start living renal transplants?**

SCB Medical College and Hospital in Cuttack is the first government hospital in the state to start living donor renal transplantations. In 2022, AIIMS Bhubaneswar initiated its living kidney transplant program, performing 15 successful surgeries in 2023. By 2024, we introduced deceased kidney transplant program, completing four transplants in the same year. To date, our team has achieved a total of 34 living and four deceased kidney transplants, demonstrating our commitment to improving transplant outcomes for patients.

**To cite :** Pattnaik B. Odisha - An Emerging State's Experience with Deceased Organ Donation. Indian Transplant Newsletter. 2024 Oct-Dec; 23(4):p4. DOI: 10.64384/ITN.2024.067

### **Are there plans to start other organ transplants?**

We have already obtained the license for liver transplants, and our advanced liver transplant ICU is getting fully equipped and ready for implementation. The Surgical Gastroenterology team is already doing independent liver retrievals, and soon going to start with both living and deceased donor liver transplants. Additionally, there are plans to initiate other transplant programs such as hand & cornea.

### **What are the other transplant centers in Odisha?**

When discussing the landscape of organ transplantation in Odisha, it's heartening to see the commitment of various institutions to support those in need. AIIMS Bhubaneswar and SCB Cuttack are shining examples of compassion in action, as these leading public sector hospitals strive to provide budget-friendly transplant options for underprivileged patients. Their dedication makes a significant difference in the lives of many individuals and families facing health challenges. Additionally, private centers like SUM Ultimate, KIMS Bhubaneswar, Apollo Hospital Bhubaneswar, and Utkal Hospitals are taking important steps to offer organ transplants, further contributing to the well-being of the community. This collaborative effort between public and private sectors is truly paving the way for improved healthcare access in Odisha, showcasing a united front in support of those in desperate need of life-changing treatments.

### **Tell us about the initiatives taken to promote organ donation.**

The state is launching various initiatives to promote organ donation by collaborating with NGOs, schools, police, and district administration.

- State honors the deceased organ donors with "guard of honor"
- The "Suraj Award" is presented to the deceased donor's next-of-kin

### **What, according to you, are the challenges for organ donation and transplantation in Odisha? And opportunities?**

With the right combination of public awareness, improved affordability, and robust policy, Odisha has a strong opportunity to emerge as a regional leader in organ transplantation. By addressing current challenges and seizing available opportunities, the state can improve organ donation rates, reduce transplant waiting times, and ensure that life-saving treatments are accessible to all.

### **Any other thoughts before we close?**

The organ donation and transplantation program at AIIMS Bhubaneswar stands as a model of excellence, driven by strong leadership, multidisciplinary coordination, supportive organization, and respect for donor families. Under the visionary leadership of Dr. Ashutosh Biswas, Executive Director, the program has achieved remarkable milestones in transplantation. The involvement of SOTTO, ROTTO, and NOTTO has been instrumental in enabling effective organ retrieval, donation, and transplantation.

In few months' time, AIIMS, Bhubaneswar will start and sustain the much-needed liver transplantation, which will save many lives lost due to acute and end-stage liver diseases.

Interviewed by Ms. Pallavi Kumar,  
Executive Director, MOHAN Foundation



## 17<sup>th</sup> National Transplant Games by Narmada Kidney Foundation



### Dr. Bharat V. Shah

Director, Institute of Renal Sciences,  
Gleneagles Hospital, Mumbai  
Director, Advanced Transplant Diagnostics  
and Immunogenetics  
Gen. Secretary, ZTCC, Mumbai  
Managing Trustee, Narmada Kidney Foundation  
Past-President, Indian Society of Nephrology, West Zone  
Past-President, Mumbai Nephrology Group

Narmada Kidney Foundation (NKF) is a registered Non-Governmental Organization (NGO) set up in 1993 to create awareness about kidney diseases, organ donation and transplantation. One of its major activities is to conduct national transplant games every year.

The transplant games aim to show how transplant recipients return to normalcy after transplant. In the past, transplant games were conducted sporadically in India. Narmada Kidney Foundation (NKF) is the first organization in the country to consistently organize National Transplant Games (NTG) from 2008. This year was the 17<sup>th</sup> NTG.

The NTG show how people with organ failure live life to their fullest after transplant. Besides transplant recipients, living donors who have donated kidney or part of the liver also participate in the NTG to show that they continue to remain as normal after donation as they were before donation. This creates huge confidence among potential transplant recipients and donors.

This year, the National Transplant Games supported by the Indian Society of Organ Transplantation (ISOT) and Ghatkopar Jolly Gymkhana saw participation of about 300 living donors and transplant recipients from different parts of the country. The games were held at Ghatkopar Jolly Gymkhana and inaugurated by Dr. Sanjay Kolte, President of ISOT. Also present were Dr. Bipin Chevale, CEO, Gleneagles Hospitals, Parel, Mumbai, Shri Rajnikant Shah, Chairman, Ghatkopar Jolly Gymkhana and the committee members of Ghatkopar Jolly Gymkhana.

The Games started with lighting of Torch by Dr. Bharat Shah, founder member and managing trustee of NKF. The torch was then passed on to the donors and recipients, representing shared journey of life, hope and survival through organ donation and transplantation.

The event brought together heart, liver, kidney, and even hand transplant recipients, showcasing their strength and resilience. Living donors who donated kidneys or a part of their liver also participated in the games.



The Games featured events like relay running, pickle ball, box cricket, badminton, table tennis, carom and chess. A new game Petanque was also introduced this year.

These games are very important for transplant recipients and donors as well. You get to know your potential and when you come here you get inspired by seeing so many people doing various activities which you thought you never would after transplant said Mr. Digvijay Singh (Jabalpur, Madhya Pradesh). He had his kidney transplant in 2011 and is a regular participant in NTG. The NTG inspired him to participate and represent India in world transplant games in Newcastle in 2019 and Perth in 2023.

Mr. Bhagwan Reddy and Mr. Hitesh Soni who participated thanked NKF for organizing these games.

Sixty-seven years old Shaikh Ansaf Khasam who underwent liver transplant in 2013, with his son as donor, showcased his incredible skill and perseverance in the carom competition.

The event ended with prize distribution ceremony where winners from various competitions were honoured for their prize winning performances. Medals and certificates were presented to the winners.

This celebration served as a beacon of hope for thousands and strengthened the message of organ donation and transplantation, said Mr. Dnyanraj Patkar, a transplant recipient himself and president of Narmada kidney Foundation.

**To cite :** Shah B V. 17th National Transplant Games by Narmada Kidney Foundation. Indian Transplant Newsletter. 2024 Oct-Dec; 23(4):p5. DOI: 10.64384/ITN.2024.068



## Advancing Skills in Liver Transplantation: A Workshop for Transplant Coordinators held in Hyderabad

Transplant coordinators, including clinical coordinators specializing in liver transplantation, were given an opportunity to improve their knowledge through a comprehensive one-day workshop under the aegis of the LTSI Conference in Hyderabad. The workshop was organised by NATCO and MOHAN Foundation on Nov 29, 2024, at the Novotel Convention Centre, HITEC City, Hyderabad.



Dr. Mohamed Rela (4th from left), President of LTSI and other office bearers at the inauguration

During the inauguration, Dr. Ravi Mohanka and Dr. Abhideep Choudhury urged the transplant coordinators to improve their skills and write articles to showcase their work. Dr. Mohamed Rela, President of the Liver Transplant Society of India (LTSI), made a significant announcement, pledging to make transplant coordinators a specific category within the organization, further recognising their pivotal role in the transplant ecosystem.

### Key Highlights of the Workshop:

The workshop covered a broad spectrum of topics and facilitated presentation and discussions amongst the transplant coordinators and experts, as follows:

- Evaluation of a liver donor
- Post liver transplant protocols
- Establishing liver transplant system in Tier II cities in India
- Documentation in international patients
- International organ allocation policies

### National State-Based Liver Allocation Practices

Mrs. Arati Gokhale, Chief Coordinator of ZTCC Pune, opened the discussion by outlining the guidelines established by NOTTO, offering a national framework for organ allocation.

The allocation policies for liver for the following states were discussed in detail :

- |                  |              |
|------------------|--------------|
| • Andhra Pradesh | • Karnataka  |
| • Telangana      | • NCR        |
| • Maharashtra    | • Kerala     |
| • Gujarat        | • Tamil Nadu |

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The session highlighted the organ-sharing mechanisms and the criteria for prioritizing patients on the urgent and supra-urgent lists. This interactive session shed light on the diversity of practices across the country while emphasizing the need for standardized, transparent, and ethical allocation policies.

### From Legality to Autonomy: Amplifying Living Donor Voices

The session moderated by Dr. Sonal Asthana, Lead Consultant, HPB and Liver Transplant Surgery, Aster Hospitals, Bengaluru was a compelling exploration of the rights, challenges, and experiences of living organ donors. The esteemed panel included:

- Dr. Viniyendra Pamecha, Head - Liver Transplant, ILBS, Delhi
- Dr. Gomathy Narasimhan, Senior Consultant, Multi-Organ Transplant, Dr Rela Institute and Medical Center, Chennai
- Mr. Girish Shetty, Senior Transplant Coordinator, Apollo Hospitals, Hyderabad
- Prof. (Dr.) G. B. Reddy, Legal Expert, Hyderabad
- Mrs. P.R.L. Kiranmai, Liver donor, Hyderabad
- Ms. Jaya Jairam, Project Director, MOHAN Foundation, Mumbai

The session opened with a poignant video featuring Ms. Sudha Bhamidipati, who shared her journey as a liver donor for her husband, setting an empathetic tone for the discussion.

Dr. Sonal posed incisive questions to the panel - presence of independent living donor advocates, timing and role of psychological counseling in the evaluation process, rights of living donors. Dr. Gomathy shared insights from her research on gender disparities among living liver donors, drawing data from two major Indian registries. The session highlighted the importance of recognizing and amplifying donor voices, fostering discussions that advance both ethical practices and donor well-being.

### Case studies - Coordination in Liver Transplantation

Dr. Gomathy Narasimhan concluded the event with an engaging session centered on three complex case studies in liver transplantation. These included scenarios involving a marginal donor, a split liver donation, and managing the varied expectations of different surgeons. In an interactive approach, Dr. Gomathy invited delegates to role-play the scenarios, encouraging them to step into the shoes of coordinators and decision-makers. This dynamic format sparked lively discussions and active participation, providing valuable insights into real-world challenges and solutions in liver transplantation coordination. The session was a standout, leaving the audience enriched with practical knowledge and collaborative strategies.



## Ethics in Action - Annual Workshop for Transplant Coordinators

The Network and Alliance of Transplant Coordinators (NATCO) successfully hosted its 17<sup>th</sup> Annual Conference on October 19-20, 2024, at the KD Hospital Auditorium in Ahmedabad. The two-day event, graciously hosted by KD Hospital, brought together experts, doctors, and transplant coordinators under the theme "Ethics in Action," focusing on ethical practices and the indispensable role of transplant coordinators in advancing organ donation in India.

The conference began with an inaugural ceremony led by Dr. Sunil Shroff, Managing Trustee of MOHAN Foundation, and Dr. Rakesh Joshi, Medical Superintendent of Civil Hospital, Ahmedabad. Both dignitaries emphasized the significance of ethical considerations in organ donation, setting the tone for the event. A "Handbook for Registering Hospitals as Transplant Centers," developed by NATCO was released during the inaugural ceremony.



The first day featured discussions on successful deceased organ donation programs in Gujarat, Tamil Nadu, and Manipur, as well as innovative approaches to post-transplant patient care. A session on challenges and achievements faced by NGOs welcomed valuable input from organizations such as MF Jaipur Citizen Forum, Muskaan, ORGAN India, Shatayu, Shine India, Rotary Club of Organ Donation, Eye Bank Society of Rajasthan, and Bengal Organ Donation Society.



The highlight was the **Swami Narayan Memorial Oration** by **Padmashree awardee Dr. Janak Palta McGilligan**, whose narrative underscored the societal and ethical impact of organ donation.

The screening of *God Vulture and Human*, a documentary by Rishiraj Agarwal and co-produced by Prof. Rajesh Chandwani, left a profound impact. It shed light on the human and ethical aspects of organ donation, emphasizing the critical role of transplant coordinators. Delegates also participated in a free paper session, presenting research and field experiences evaluated by a panel of esteemed judges.

On the second day, discussions addressed organ donation trends at government hospitals, including insights from AIIMS Raipur, AIIMS Bhubaneswar, JNIMS Imphal, and GMC Nagpur. Other topics included leveraging government schemes, improving documentation skills, and exploring crowdfunding for underprivileged patients. These sessions offered practical strategies to empower transplant coordinators and enhance their effectiveness.

"Congratulations on organizing and successfully executing the 17<sup>th</sup> Annual NATCO Conference. Every component was well thought out. Although I am not a transplant coordinator, I gained a great deal of knowledge over the past two days and had the opportunity to meet many wonderful and inspiring individuals." - **Ms. Hemali Ajmera**

"The hallmark of exceptional transplant programs globally is the presence of outstanding transplant coordinators. This conference truly showcased their dedication and expertise, reaffirming the importance of their role in India's expanding transplantation programs." - **Mr. Atul Agnihotri**

"It was an honour to chair a session and engage with esteemed colleagues dedicated to advancing deceased organ donation. The collaborative environment and insights gained were invaluable, and I deeply appreciate the warm hospitality extended by NATCO." - **Dr. Chintan Chaudhari**

The Conference provided a valuable platform for knowledge sharing, professional growth, and networking. It reaffirmed the organization's unwavering commitment to ethical practices and the advancement of transplantation efforts in India. By fostering dialogue, practical learning, and sharing insights into the challenges and rewards of their work, the conference continues to inspire and empower transplant coordinators, strengthening the country's transplantation ecosystem.



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## Need for Legislations in India to Safeguard Living Donors



**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.*

### 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.

### 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.

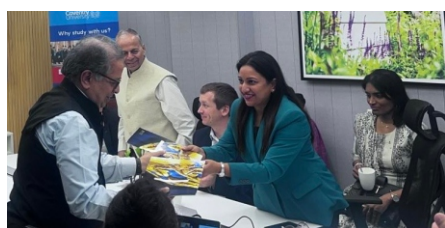
Such measures would not only encourage more individuals to donate but also foster a culture of organ donation built on respect, care, and systemic support.

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**To cite:** Jairam J. Need for Legislations in India to Safeguard Living Donors. Indian Transplant Newsletter. 2024 Oct-Dec; 23(4):p8-9. DOI: 10.64384/ITN.2024.071

## Coventry University, Warwickshire NHS Trust, and University Hospitals Coventry have joined forces with MOHAN Foundation to Advance Global Organ Donation and Transplantation



On October 16, 2024, a Memorandum of Understanding (MoU) was signed between Coventry University and MOHAN Foundation. This strategic collaboration aims to run

educational modules in organ donation and transplantation to make it available globally and further collaborative research.

The MoU exchange ceremony was held at Coventry University Group's India Hub in New Delhi with dignitaries such as Michael Houlgate (Deputy Director India at the British Council), Professor Nithya Krishnan (Consultant at University Hospitals Coventry and Warwickshire (UHCW) NHS Trust), Dr Sunil Shroff (Managing Trustee, MOHAN Foundation), Jonathan Young (Chief Medical Officer, University Hospitals Coventry and Warwickshire (UHCW) NHS Trust) and many others who attended online.

The chief guest, former MP Dr Vikas Mahatma, delivered keynote remarks and congratulated both the teams for this exciting project.

**To cite:** Kumar P. Coventry University, Warwickshire NHS Trust, and University Hospitals Coventry have joined forces with MOHAN Foundation to Advance Global Organ Donation and Transplantation. Indian Transplant Newsletter. 2024 Oct-Dec; 23(4):p9. DOI: 10.64384/ITN.2024.072

### Experts Comments on Transplantation Tie-up

Nithya Krishnan, Consultant Transplant Nephrologist at UHCW NHS Trust, was appointed as Professor of Clinical Health at Coventry University to lead on research and education links with India. She said, "These developments are very exciting, and we want to make training courses and materials on various aspects of organ donation and transplantation available for doctors and nurses globally. We also plan to advance research into the role of AI in improving transplant services. Our aim is to put UHCW NHS Trust and Coventry University on the world map of transplantation."

Leena Kukreja, Regional Managing Director of Coventry University Group's India Hub, commented, "Coventry University Group is committed to benefiting the communities we serve, in the UK and internationally, and we look forward to sharing our research and teaching expertise to support this collaboration with MOHAN Foundation on organ transplantation. India's large and skilled talent pool, young population and thriving research sector make the country ideal for the Group's collaborative working approach, which saw the launch of the India Hub earlier this year to create long-term strategic partnerships with Indian Government, industry and higher education institutes."

## Liver Allocation Practices in Different States Across India

In the recent years, liver transplantation has gained momentum in many states of India. Across the country, 4,491 liver transplants were carried out in 2023, of which 840 (18.7%) involved deceased donors. The National Organ Tissue Transplant Organization (NOTTO) has set guidelines for patient listing and liver allocation. Even though these guidelines have been adopted, there are some variations and state-specific protocols which are seen.

**NOTTO guidelines for allocation of deceased donor liver**  
([www.notto.mohfw.gov.in](http://www.notto.mohfw.gov.in))

### Recipient Registration and Listing

- Patient is to be registered by the concerned hospital
- Patient should be registered only in one hospital
- Liver Advisory Committee will approve the registration and urgency criteria
- Standard listing
  - a. Patients with a MELD (Model for End-stage Liver Disease) score greater than 15
  - b. Patients with cirrhosis of liver with hepato-cellular carcinoma should be with-in UCSF criteria
- Super-urgent listing
  - a. Primary Non-Function (PNF) of liver allograft
  - b. Living liver donor who develops life threatening liver failure
  - c. Early Hepatic Artery Thrombosis (HAT) requiring re-transplant
  - d. Fulminant Hepatic Failure (FHF) meeting the King's College Hospital criteria
- Contraindications to listing for liver transplantation
  - a. MELD Score < 15
  - b. Severe cardiac or pulmonary disease, who is unfit for general anaesthesia
  - c. AIDS
  - d. Hepatocellular carcinoma beyond UCSF criteria
  - e. Uncontrolled sepsis
  - f. Intrahepatic Cholangiocarcinoma
  - g. Extra-hepatic malignancy transplant
- Status of the listed patient must be updated monthly. For Super-urgent patients, status update is required daily.

### Allocation Principles

- Sequence of allocation of organs shall be in following order: State list-Regional List-National List
- Livers from pediatric donors (< 16 years) are prioritized for pediatric recipients; if none, then adults.
- O blood group liver is given first to O recipients, then to others
- Other than O blood group (A, B and AB), liver will be preferably allocated to the same group, otherwise to AB

### Allocation Algorithm

Check Blood Group & age of donor

Allocation will be done based on the medical urgency

- Super-urgent list
- Simultaneous multi-organ transplant based on waiting time list
- Single organ (liver) transplant

**To cite :** Kanvinde H. Liver Allocation Practices in Different States Across India. Indian Transplant Newsletter. 2024 Oct-Dec; 23(4):p10-11. DOI: 10.64384/ITN.2024.073

### Types of donor hospitals

- Donation from a Transplant Hospital - Liver will be allocated to local transplant hospital
- Donation from a NTOC - Liver will go to the common pool and allocated as per the rota

### Liver retrieved from a government hospital

- Government hospitals other than Army Hospital R&R, by rota
- Army Hospital R&R, Delhi
- Private hospitals as per the rota

### Liver retrieved from a private hospital

- Rota of private hospitals
- Government hospitals other than Army Hospital R&R as per rota
- Army Hospital R&R, Delhi

### Karnataka - Jeevasarthakathe (SOTTO)

- The State is divided into five zones - Bangalore, Mysore, Mangalore, Hubballi, and Kalaburagi.
- Liver allocation is prioritized based on the zone, medical urgency (MELD score), blood group compatibility.
- Institutions within each zone follow a clear hierarchy for allocation: super-urgent recipients, in-house patients, and rotation-based allocation (rota) for other centers.
- Priority is given to supra-urgent cases with compatible blood groups.

**Delson Ashley Dsouza**

*Transplant Coordinator, Aster CMI Hospital, Bangalore*

### Mumbai - ZTCC (Zonal Transplant Co-ordination Centre)

- There is no difference in distribution between government and private hospitals. The organs are distributed chronologically according to the registration date.

**Rohini Nalawade**

*Sr. Transplant coordinator, Sir H.N. Reliance Foundation Hospital & Research Centre, Mumbai*

### Tamil Nadu - TRANSTAN

- A web based allocation system is followed to safeguard from fraudulent registrations.
- Supra-urgent list - Patient is considered only if the registration and approval is done 6 hours prior to a donor alert. Approval is done by the state liver advisory committee
- In-house liver - Recipient is chosen from the list based on blood group compatibility, clinical suitability, MELD score, and waiting time.
- If no suitable recipient is found at that hospital, liver will be allocated as per the zonal rota system; then to the state rota.
- The State is divided into three zones, and the hospitals from the same zones are given priority. If three consecutive hospitals decline a liver offer, it is opened to all other zones.
- Hospitals have 45 minutes to accept the organ offer.

**A Johnson**

*Senior Manger, Transplant Services, Apollo Hospitals, Chennai*



## Gujarat - SOTTO

- Comprehensive Data Integration: The SOTTO portal is designed for seamless coordination between hospitals, allowing real-time updates and efficient communication.

### MELD Score Update Periods for all types of patients:

- Minimum MELD score of 8 is required for listing.
- MELD  $\leq$  10: Update every 12 months (reports not older than 30 days)
- MELD 11-18: Update every 3 months (reports not older than 14 days)
- MELD 19-24: Update every 1 month (reports not older than 7 days)
- MELD  $\geq$  25: Update every 7 days (reports not older than 48 hours)
- For pediatric patients, the Pediatric End-Stage Liver Disease (PELD) score is used.

### Donor in a licensed transplant hospital

- Priority is given to a recipient registered from that hospital.
- Priority is given to multi-organ listing patients first, followed by single-organ (liver) patients based on MELD scores.

### Donor in a government non-transplant organ retrieval center

- First, third, and fifth organ donor's livers go to government hospital pool recipients.
- Second and fourth organ donor's livers go to private hospital pool recipients.

### Donor in a private non-transplant organ retrieval center

- First, third, and fifth organ donor's livers go to private hospital pool recipients.
- Second and fourth organ donor's livers go to government hospital pool recipients.

### Exceptions in Allocation

In cases where a deceased donor's near relative requires an organ, priority is granted, only once, within a ten-year period.

**Nikhil Y Vyas**

DGM - Organ Transplant, KD Hospital Gujarat

## Kerala - Mrithasanjeevani (K-SOTTO)

- K-SOTTO regulates the liver allocation process and follows the guidelines developed through the consensus of stakeholders in the liver transplant process.
- Given the logistics of transporting liver across the state and in the interest of keeping cold ischemia time low, the state has been divided into three zones (North, Central, and South).
- Liver-specific subcommittee oversees the organ allocation process.

### Types of listing:

1. Elective liver transplantation
2. Super urgent liver transplantation

### Elective liver transplantation:

- The recipients must be registered (with K-SOTTO) for at least 24 hours before being considered for a potential offer.
- When the institution is offered a liver, the transplant unit can decide on the recipient from the list based on blood group compatibility, clinical suitability, MELD and waiting time.
- If there are no suitable recipients in that hospital, the offer will be passed to the next hospital as per the zonal rota system and then to the state rota.
- Allocation from NTORC for elective transplants will also follow the rota system.

### Super urgent liver transplantation:

- Details of the acute liver failure patients must be submitted to the liver expert committee via K-SOTTO in the prescribed format.
- Allocation will be open to them only after getting approval from the liver expert committee.

**S Saranya**

Kerala State Organ and Tissue Transplant Organization (K-SOTTO)

## Himalayan International Transplant Conference, Nepal 2024

"The Himalayan International Transplant Conference" was held on December 14 - 15, 2024 at Everest Hotel, Kathmandu, Nepal. The theme for the conference was "Promoting Organ Donation in the Developing World".

At the conference, Ms. Pallavi Kumar, Executive Director, MOHAN Foundation addressed the audience on "Incentives on Organ Donation- A worldview". Ms Pallavi Kumar's presentation explored various incentive models worldwide to encourage organ donation. It reviewed incentive structures across different countries, including



both financial and non-financial models. These incentives range from prioritization on transplant lists, health insurance discounts, funeral expense reimbursements, and

tax benefits to controversial financial compensation models. International guidelines, such as those from the World Health Organization (WHO), the Istanbul Declaration, and the Council of Europe, were analysed to provide a regulatory context. Examples from countries like Iran (with a regulated kidney market), the United States, Israel, Singapore, Chile, and India illustrate various models' successes and challenges.

Other esteemed speakers from several countries like Japan, Netherlands, USA, UK covered various topics under the following themes:

- Transplant pathology and immunology
- Organ donation
- Live renal transplantation
- Challenges in transplantation

**To cite :** Kumar P. Himalayan International Transplant Conference, Nepal 2024. Indian Transplant Newsletter. 2024 Oct-Dec; 23(4):p11. DOI: 10.64384/ITN.2024.074



## Anant Acharya

### A Kidney Recipient & an Organ Donation Ambassador

Life has a way of surprising us, often in ways we least expect. At 35, I faced one of the toughest challenges of my life a diagnosis of chronic kidney disease (CKD). For someone who lived a disciplined life - no smoking, no drinking - this diagnosis felt very unexpected. Faced with the choice between dialysis or a transplant, my wife's (Shradha Acharya) generous decision to donate her kidney gave me not only a second chance at life but also a renewed sense of purpose.

**Mr. Anant Acharya**  
Software Engineer at SAP  
Bengaluru

Last few years of my journey is defined by resilience, gratitude, and a desire to contribute to causes bigger than myself. This experience has shaped my perspective, allowing me to see both my personal and professional roles through a broader lens.

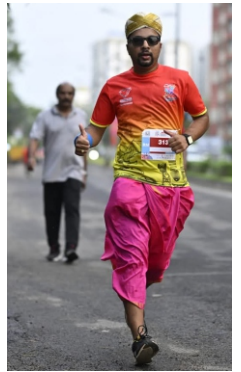
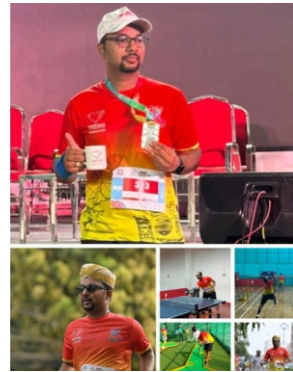
Thanks to **MOHAN Foundation** for giving me an opportunity in engaging in philanthropic activities and providing me a platform to reach the larger audience. Becoming an organ donation ambassador has been a deeply fulfilling role for me. It allows me to connect with individuals and families who are considering organ donation, providing them with guidance and clarity. My own journey gives me the ability to address their fears, share real-life insights, and offer both practical and emotional support.

I enjoy running, hence post-transplant, I am participating in many Runs (5km or 10 km) to create awareness on the importance of physical activity for the transplant community. I always use these platforms to talk about organ donation and preventive measures for organ failure, which includes importance of monitoring blood pressure and Diabetes to the IT folks.

I have my own signature costume (Dhoti), which I wear and run for the awareness on the organ donation. I do participate in Regional and National transplant games and ensure to connect with our community to build my network and test my fitness journey.

I would thank my wife for giving me this second life and with which I can drive awareness on "Organ Donation" which is the need of the hour.

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