

# INDIAN TRANSPLANT NEWSLETTER

A quarterly publication from

MOHAN FOUNDATION

MULTI ORGAN HARVESTING AID NETWORK

Vol.23 Issue No.3

July 2024 – September 2024

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## Editorial Desk

### National Organ and Tissue Transplant Organization Takes a Step Forward in the Right Direction

The National Organ and Tissue Transplant Organization (NOTTO), under the Directorate General of Health Services of the Ministry of Health & Family Welfare, organized a two-day event called the "Chintan Shivir" on August 30 - 31, 2024. The primary goal of this event was to bring together key stakeholders from across India involved in organ donation and transplantation, to discuss necessary reforms for improving organ and tissue donation in the country. The discussions focused on enhancing technology, streamlining processes, and revising the legislative framework governing organ transplantation.

To ensure a comprehensive review, ten working groups were formed to address different areas of the organ transplantation ecosystem. Each group consisted of 10 to 20 members, including a representative from NOTTO, and held several virtual meetings prior to the event. During the physical meeting, each group presented their findings and proposed reforms. This marked the first time such a wide-ranging, collaborative effort had been made since the inception of NOTTO (2014), providing a platform for states and stakeholders to raise concerns and propose solutions.

#### Key Outcome: Need for Uniform Policies

One of the most significant conclusions of the Chintan Shivir was the realization that a uniform national policy for organ donation and transplantation is essential. This would ensure that all states and the Union Territories follow the same procedures, making the program more efficient and seamless. However, the challenge is that health is a state subject in India, making national policy implementation complex. Collaboration between central and state governments was seen as crucial for the success of these reforms.

#### Key Problems Identified:

1. Organ retrieval and utilization inefficiencies
2. Training and capacity gaps
3. Legislative and policy gaps
4. Lack of awareness among public and medical professionals

#### Proposed Solutions:

1. Improving organ retrieval and allocation
2. Expanding training and capacity building
3. Policy and legislative reforms
4. Public awareness and social mobilization

The Chintan Shivir has laid the groundwork for a more efficient organ transplantation ecosystem in India by emphasizing the need for uniform policies, enhanced training, and increased public awareness. These reforms, once implemented, could significantly improve organ donation rates and ensure better utilization of donated organs.

Chintan Shivir is discussed in detail on page 11.

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**To cite :** Shroff S. National Organ and Tissue Transplant Organization Takes a Step Forward in the Right Direction. Indian Transplant Newsletter. 2024 Jul-Sep; 23(3):p1.



## Combined Whole-Eye and Partial-Face Transplant: A Milestone Towards Restoring Vision

After surviving a severe high-voltage electrical accident, 46-year-old military veteran Aaron James underwent the world's first combined whole-eye and partial-face transplant in May 2023 at NYU Langone Health. Research published in September 2024 in the Journal of the American Medical Association (JAMA) titled "Combined Whole Eye and Face Transplant – Microsurgical Strategy and 1-Year Clinical Course" highlights the clinical outcomes and data from the first year post-transplant. Remarkably, the transplanted donor eye has maintained normal blood flow and pressure. While vision has not yet been restored, electroretinography (a technique that measures the retina's electrical response to light) has shown retinal activity in the transplanted eye. The successful revascularization achieved in this case may represent a significant step towards the future possibility of whole-eye transplants aimed at restoring sight.

**To cite :** Shroff S, Suriyamoorthi S. Combined Whole-Eye and Partial-Face Transplant: A Milestone Towards Restoring Vision. In the news. Indian Transplant Newsletter. 2024 Jul-Sep; 23(3):p2.

## British Transplant Games 2024

The 46<sup>th</sup> Annual British Transplant Games 2024 took place from August 1<sup>st</sup> to 4<sup>th</sup> in Nottingham. The event featured 26 different sports, allowing transplant recipients of all ages to engage in various sporting events. The Games aim to raise awareness about the importance of organ donation, encourage transplant recipients to maintain active lifestyles, and honour the memory of donors and their families.

Held in different host cities every summer, the Games bring together teams from hospitals across the UK to compete in a variety of sports. This four-day event conducted every year attracts around 1,000 transplant athletes and thousands of supporters.

Organized on behalf of Transplant Sport, the Games were established in 1978 by Maurice Slapak CBE, a consultant surgeon, who brought together his patients and other transplant recipients to hold the first Transplant Games in Portsmouth.

**To cite :** Shroff S, Suriyamoorthi S. British Transplant Games 2024. In the news. Indian Transplant Newsletter. 2024 Jul-Sep; 23(3):p2.



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A quarterly publication from MOHAN Foundation  
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## Myanmar's Crisis is Driving the Surge in Illegal Organ Trade

The economic crisis brought on by Myanmar's civil war has spiralled into a humanitarian catastrophe, plunging millions into hunger, desperation - and even the sale of human organs. As poverty deepens, an increasing number of people in Myanmar are resorting to selling their kidneys in a desperate attempt to escape crushing debt and survive. Many of these individuals travel to neighbouring countries, such as India, to undergo the procedures, finding it the only quick-fix solution left to them in the face of such bleak circumstances. These unethical transplants are facilitated by agents and intermediaries who use falsified documents to get around laws in nations like India and Myanmar, where the selling of organs is prohibited.

With economic collapse, political instability, and civil conflict tearing the country apart, desperation has reached a point where some turn to Social Media Apps to advertise the sale of their organs.

For those involved, the kidney trade can seem like a lifeline, offering temporary relief from poverty. However, there are serious exploitation concerns underlying this unsettling development. The situation raises urgent questions about the ethical consequences of such transactions and the need for stronger legal frameworks and support systems to protect those at risk from exploitation.

**To cite :** Shroff S, Suriyamoorthi S. Myanmar's Crisis is Driving the Surge in Illegal Organ Trade. In the news. Indian Transplant Newsletter. 2024 Jul-Sep; 23(3):p2.

### FORM – IV

**Place of Publication:** Chennai  
**Periodicity of its Publication:** Quarterly  
**Printer's Name:** Krishna Prints  
**Nationality:** Indian  
**Address:** Chennai  
**Publisher's Name:** Sunil Shroff  
**Nationality:** Indian  
**Address:** MOHAN Foundation, Toshniwal Building, 3<sup>rd</sup> Floor, 267 Kilpauk Garden Road, Chennai 600010  
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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  
Date: 30<sup>th</sup> September 2024      Signature of Publisher



## Budget Growth of the National Organ Transplant Program

The National Organ Transplant Program in India is crucial for patients with end-stage organ failure. The program's budget has seen steady increase over recent years. In the fiscal year 2022-2023, the allocated budget of the program's financial journey was 9.11 crores. Moving into 2023-2024, the revised budget saw a notable increase to 11.00 crores. The most striking testament to the program's trajectory came in 2024-2025, when the allocated budget soared to 15.00 crores.

- Significant budget growth reflects societal recognition and commitment to organ transplantation
- Enhanced resources support improved clinical outcomes and expanded donor networks
- Commitment to healthcare equity ensures accessibility to all socioeconomic groups

To address the issue of equitable access, it is crucial for the government to enhance organ transplant services in public sector hospitals, particularly in government-run medical colleges. These institutions have the potential to conduct kidney transplants but often lack the necessary expertise and manpower. To address these gaps, a robust public-private partnership should be developed. This approach will help provide transplant services to marginalized and disenfranchised populations, ensuring that everyone, regardless of their economic status, can benefit from these life-saving procedures.

**To cite :** Shroff S, Suriyamoorthi S. Budget Growth of the National Organ Transplant Program. In the news. Indian Transplant Newsletter. 2024 Jul-Sep; 23(3):p3.

## "Truly Noble": AIIMS Delhi Commends Sitaram Yechury's Family for Donating His Body for Medical Research

Veteran Left leader and General Secretary of the Communist Party of India (Marxist), Sitaram Yechury, passed away on September 12, 2024. His family has donated his body to All India Institute of Medical Sciences (AIIMS), New Delhi, for teaching and research purposes. By choosing to donate his body to science, Yechury follows a tradition upheld by several prominent Left leaders, who donated their bodies including Buddhadeb Bhattacharjee (in August 2024 to Nil Ratan Sircar Medical College in Kolkata), Jyoti Basu (in 2010 to SSKM Hospital, Kolkata), and Somnath Chatterjee (in 2018 to SSKM Hospital, Kolkata).

**To cite :** Shroff S, Suriyamoorthi S. "Truly Noble": AIIMS Delhi Commends Sitaram Yechury's Family for Donating His Body for Medical Research. In the news. Indian Transplant Newsletter. 2024 Jul-Sep; 23(3):p3.

## Tamil Nadu Observes State Organ Donation Day

On September 23, 2024, at Kalaivanar Arangam in Chennai, the Tamil Nadu State Organ Donation Day was observed. State Organ Donation Day is celebrated on this day every year in honour of Hitendran, whose organs were donated in 2008. The families of deceased donors as well as the transplant teams from both public and private hospitals were acknowledged by Ma. Subramanian, Tamil Nadu's Minister for Health and Family Welfare. During the event, the Annual Book of TRANSTAN, detailing the state's yearly performance in deceased donations and transplants was released.

"Between September 2023 and August 2024, a total of 1393 organs and tissues have been retrieved from 258 brain-dead donors. Additionally, 14,300 people have registered online for organ donation. The state government's efforts to honour deceased donors, combined with focused awareness initiatives, have significantly boosted public understanding of organ donation.", stated Health Minister Ma. Subramanian.

Several government medical college hospitals, such as those in Dharmapuri, Krishnagiri, Tirupur, Theni, and Namakkal, have initiated deceased donation programs. Among public hospitals, the Rajiv Gandhi Government General Hospital, Chennai reported the highest number of deceased donations, with 35 donations. This increase in donations at government hospitals has also led to a rise in transplants within these institutions. During his address at the event, Dr. N Gopalakrishnan, Member Secretary of TRANSTAN, emphasized that TRANSTAN is currently focusing on gathering comprehensive data on transplant outcomes and patient survival rates.

**To cite :** Shroff S, Suriyamoorthi S. Tamil Nadu Observes State Organ Donation Day. In the news. Indian Transplant Newsletter. 2024 Jul-Sep; 23(3):p3.

## Indian Railways Grants 42-day Special Casual Leave (SCL) for Living Organ Donors

In an effort to recognize its employees who have chosen to donate their organs, Indian Railways has introduced an initiative that entitles them to a 42-day Special Casual Leave (SCL).

This initiative follows the Office Memorandum (OM) issued in April 2023 by the Department of Personnel and Training (DoPT), in consultation with the Ministry of Health & Family Welfare (MoHFW), which provided guidelines for granting SCL to living organ donors. In recognition of the noble act of helping another person and to promote organ donation, the government has decided to offer up to 42 days of SCL to any Central Government employee donating organ(s), as a special welfare measure in the public interest.

Welfare Measure for Railway Employees:

- All living donors who have been given approval under the Transplantation of Human Organs Act of 1994 are eligible for SCL.
- SCL is granted if the transplant surgery takes place in a railway hospital or an empanelled private institution.
- SCL cannot be combined with other types of leave, except in exceptional cases where complications arise from the surgery.

**To cite :** Shroff S, Suriyamoorthi S. Indian Railways Grants 42-day Special Casual Leave (SCL) for Living Organ Donors. In the news. Indian Transplant Newsletter. 2024 Jul-Sep; 23(3):p3.



## The Transplantation Society (TTS) Congress 2024, held in Istanbul, Turkey



**TTS 2024** **ISTANBUL TURKEY**  
September 22-25  
+ Virtual October 21-23

In Person + Live Streaming

Organized in partnership with

Endorsed by



The Transplantation Society (TTS) Congress 2024, held from September 22-25, 2024, in Istanbul, Turkey, served as a platform for sharing cutting-edge scientific discoveries, clinical practices, and policy updates that shape the future of transplantation. The congress brought together experts, researchers, clinicians, and professionals from across the world to discuss the latest advancements, research, and innovations in organ transplantation.

The TTS featured a diverse array of sessions, workshops, and abstract presentations focused on critical areas such as organ procurement, living and deceased donation, immunology, ethics, organ preservation technology, and the use of innovative technologies like artificial intelligence and drones in the transplantation field. Special sessions, including those led by the **Indian Society of Organ Transplantation (ISOT)**, addressed the unique challenges faced by developing nations in Asia, in expanding their living and deceased donor pools.

With a focus on both clinical and scientific advancements, TTS 2024 emphasized collaboration, knowledge-sharing, and global partnerships aimed at improving organ donation systems and patient outcomes worldwide. It also provided a space for healthcare professionals to connect, exchange ideas, and celebrate achievements in the transplantation community.

The plenary sessions served as key platform for presenting the latest advancements and future directions in transplantation science. **Dr Elmi Mueller, President of TTS 2024** offered an insightful perspective on the global transplantation landscape, focussing on **overcoming disparities in organ access** in developing nations. She emphasized the critical need for equitable healthcare solutions. One of the standout moments was the powerful talk **'Resilience and defying the odds in transplantation'**, by **Adam Alderson**, in which he shared his remarkable personal story as a **multi-organ recipient**, underscoring the emotional and physical challenges, and left a lasting impact on the audience. Other key plenary topics included groundbreaking advancements in **xenotransplantation**, improving access and outcomes in transplantation and a compelling talk featuring a journalist's perspective on the experience and harsh realities in organ trafficking.

As a renowned global forum, TTS 2024 continues to play a pivotal role in shaping the future of organ transplantation and saving lives through innovation and collaboration.

Several prestigious awards were presented during the TTS 2024, celebrating exceptional contributions to the field of transplantation.

### Medawar Prize

The **Medawar Prize**, named after Society co-founder Sir Peter Medawar, is recognized as the world's highest dedicated award for the most outstanding contributions in the field of transplantation.



Dr. Ronald W. Busuttil

[Read More →](#)

A distinguished figure in liver transplantation, Dr. Busuttil has been instrumental in advancing our understanding and practice of liver preservation, transplantation techniques, and organ donor management, greatly expanding the donor organ pool and improving patient outcomes globally.

An eminent leader in the field, Prof. Haberal has pioneered kidney and liver transplantation in Türkiye and broadly across the Middle East and Central Asia. His work has established critical healthcare infrastructures and legislative frameworks that have saved thousands of lives and advanced medical practices in transplantation.



Prof. Mehmet Haberal

[Read More →](#)



Dr. Shaf Keshavjee

[Read More →](#)

Renowned for developing the low potassium dextran (LPD) lung preservation solution and the Toronto Ex Vivo Lung Perfusion (EVLP) system, Dr. Keshavjee's innovations have significantly enhanced the viability and utilization of donor lungs worldwide, making critical advancements in lung transplantation.



The Transplantation Society (TTS) Congress 2024, held in Istanbul, Turkey

Outstanding Achievement in Transplantation Science

The event marked a proud moment for India's organ donation and transplantation program, as **Dr Pranjal Modi** was honoured with TTS Recognition Award for '**Outstanding Achievement in Transplantation Science (Clinical)**', a well-deserved recognition for his exceptional contribution to the field.



Dr. Haval Shirwan  
USA

Outstanding Achievement Transplantation Science (Basic)



Prof. Pranjal R. Modi  
India

Outstanding Achievement Transplantation Science (Clinical)



Prof. Vathsala Anantharaman  
Singapore

Mentorship or Education and Training Award in Transplantation



Dr. Alejandro Niño-Murcia  
Colombia

Outstanding Achievement in Transplantation (Developing Country)



The **Women in Transplantation Awards** was presented to **Dr Curie Ahn** from **Korea**, in recognition of her leadership and research in nephrology and transplantation. This award celebrates women who have significantly advanced the field of transplantation through research, policies, leadership, initiatives or other regarded contributions. The **Unsung Hero(ine) Award** was given to **Dr Wenshi Jiang** from **China** and **Dr Katayoun Najafizadeh** from **Iran**. These women were acknowledged for their community service, volunteering, mentorship or other community-based activity.



2024  
Women in Transplantation  
AWARDS



Curie Ahn  
Korea

Woman Leader in Transplantation



Wenshi Jiang  
People's Republic of China

Unsung Hero Award



Katayoun Najafizadeh  
Iran

Unsung Hero Award

MOHAN Foundation's participation at TTS Congress 2024

At the congress, Dr Sunil Shroff, Managing Trustee of MOHAN Foundation delivered a presentation on '**Empowering transplant professionals: An innovative online training initiative from a developing country**', showcasing how capacity-building through digital platforms can address challenges in resource-limited settings. In addition, he was invited to chair the session titled, 'Workshop - 25 years of plantation of deceased donor transplant program - Gujarat model for developing nations', under ISOT's sessions on 'Expanding living and deceased donor pool in Asia', held on Sep 24, 2024.

Ms. Pallavi Kumar, Executive Director, MOHAN Foundation presented on '**Enhancing healthcare equity: Public-private partnerships for organ donation and transplantation in underserved areas of North-east India**' as part of the abstract session on Ethics in organ donation, highlighting collaborative efforts to bridge healthcare gaps in India's remote regions.

Ms. Jaya Jairam, Project Director, MOHAN Foundation spoke on '**Revolutionising organ transport: The advent of drone technology for organs**' during the abstract session on technology and performance, presenting how drones are transforming the logistics of organ transportation.



To cite : Jairam J, Kumar P. The Transplantation Society (TTS) Congress 2024, held in Istanbul, Turkey. Indian Transplant Newsletter. 2024 Jul-Sep; 23(3):p4-5.

## Drive to Save Lives 2.0 - A Charity Golf Tournament



**MOHAN**  
FOUNDATION

**Rotary**  
Club of Madras Next Gen



# DRIVE TO SAVE LIVES 2.0

Friday, September 13th, 2024 | Cosmo TNGF Golf Course, Nandanam, Chennai



MOHAN Foundation and the Rotary Club of Madras Next Gen organized a charity golf tournament on September 13, 2024, at the Cosmo TNGF Golf Course in Chennai, supporting organ donation and the education of underprivileged children. MOHAN Foundation, a pioneer in organ donation since 1997, collaborated with Rotary Club of Madras Next Gen, which works for the education of underprivileged children.

With a participation of 100 players, including six from outstation, the event was filled with energy. Special invitees included liver transplant recipient Mr. Amit Prasada and heart transplant recipient Mr. Karhun Nanda. The tournament followed the Four-Ball Better-Ball format.

Supported by Apollo Hospitals, Chola MS, Globe Links, TANKER Foundation, and other notable sponsors, the tournament concluded with speeches from Dr. Sunil Shroff, Managing Trustee of MOHAN Foundation, and Mr. Yash Palsani, President of Rotary Club of Madras Next Gen, who appreciated the participants and supporters for their dedication to this life-saving cause.



To cite : Kanvinde H. Drive to Save Lives 2.0 - A Charity Golf Tournament. Indian Transplant Newsletter. 2024 Jul-Sep; 23(3):p6.



## God Vulture and Human - A Hero's Dichotomy



### God Vulture and Human

Documentary | 50 minutes | 2023

Directed and produced by **Rishiraj Agarwal**

Conceptualised and Co-produced by **Dr. Rajesh Chandwani**

### Rishiraj Agarwal

National Institute of Design, Ahmedabad

'God Vulture and Human' explores the subject of organ donation through the lens of transplant coordinators, highlighting their critical role in the process of donation, retrieval, and transplantation. Through the lives of four transplant coordinators, the film delves into the intensities of life and death, while attempting to humanize these coordinators.

The film is the brainchild of Dr. Rajesh Chandwani (Associate Professor of Human Resources Management IIM, Ahmedabad) and evolved from his research on the same subject, which emphasized the role of transplant coordinators in organ donation.

Since childhood, whenever I visited hospitals, I wondered how those working on the frontlines of healthcare cope with their own struggles and grievances. In 2016, after my father's brain surgery and 18 months of regular hospital visits, I lost him. While dealing with my own grief, I began to empathize more deeply with the grief of others. So when this opportunity came, it struck a chord in me, and I immediately started working on it.

Transplant coordinators' tireless efforts - coordinating with multiple stakeholders and counselling grieving families - make them no less than heroes; the unsung heroes who work in silence. To the organ recipients, they are often seen as lifesavers, almost god-like, while the donor families sometimes perceive them as vultures, metaphorically scavenging the remains of the dead. The film is an effort to humanize them, hence the title.

Given the heavy and grievous nature of organ donation, I aimed to handle the subject delicately, while balancing it with the realities on the ground and the dogmas associated with it. I shot the film during the second wave of COVID-19 in India, working as a one-person crew with a Sony Handycam to minimize my presence in hospitals and counselling sessions, capturing the most honest moments possible.

The film features transplant coordinators - Sudha, Bhanu Chandra, Bhanu Prakash, and Dileena in both their workspaces and personal lives, offering insights into their ambitions and challenges, along with following the two brain-dead cases.



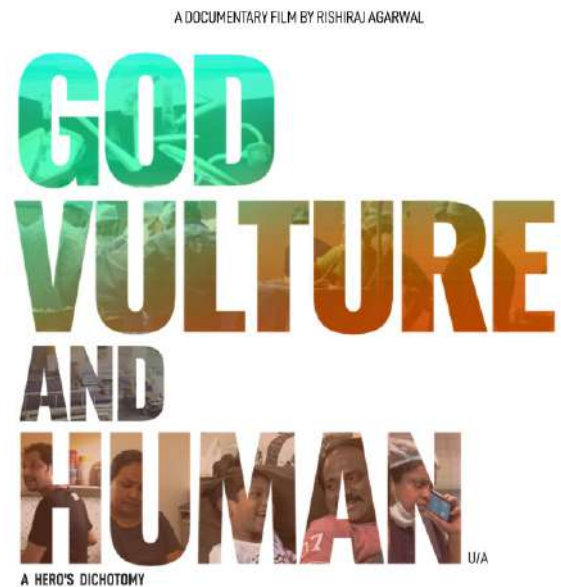
### Rajesh Chandwani

Associate Professor of Human Resources Management IIM, Ahmedabad

This film is my graduation project from the M.Des. Film & Video program at the National Institute of Design, Ahmedabad, and my first attempt at a medium-length documentary.

I hope this film finds its own course and reaches its audience.

- Rishiraj Agarwal



DIRECTION: CHENNAI KOSHYAR, SOUND & EDITED BY: RISHIRAJ AGARWAL  
PRODUCED BY: RAJESH CHANDWANI & RISHIRAJ AGARWAL, CURED BY: SHILPA DAS  
FEATURING: SUDHA SRIPURAPU, SBHANUJHANDRA DHARANIPAL, SBHANU PRAKASH & P.J. DILEENA  
SUPPORTED BY: MOHAN FOUNDATION, POSTER DESIGN: PRABHASH DHAMA



To cite : Agarwal R. God Vulture and Human - A Hero's Dichotomy. Indian Transplant Newsletter. 2024 Jul-Sep; 23(3):p7.

## Health Coverage for Kidney Transplants in the U.S.



Atul Agnihotri

Atul Agnihotri, a kidney recipient and former Fortune 500 global leader, has turned his personal journey of awaiting a transplant into a mission to help others facing similar challenges.

As the Chief Global Growth Officer for the **Alliance for Paired Kidney Donation (APKD)**, a globally renowned organization that manages an industry-leading kidney registry, Atul is working directly with government officials, policymakers, and transplant centers across over 14 countries to remove barriers to living kidney donation through ethical best practices and innovative programs and expanding Paired Kidney Exchange systems worldwide.

Recently, Atul facilitated a historical agreement between the State of Israel and the United Arab Emirates that led to a series of kidney transplants saving the lives of three women in the two countries and opening the door for more. This first ever exchange between Israel and an Arab state, is the outcome of months of behind the scenes work by the Alliance for Paired Kidney Donation, the UAE Organ Donation and Transplant Committee and the Israel Center for Transplantation.

Atul also serves as the Chairman and Executive Director of **Kidneys for Communities**, spearheading the first nationwide 'Community-Directed Donation' model in the U.S. This innovative program taps into the power of community to significantly increase altruistic kidney donations, with successful initiatives already launched for **First Responders, Farmers & Ranchers, and Children**, in partnership with leading organizations in these sectors.

Access to health coverage for end-stage renal disease (ESRD) and kidney transplants is a lifeline for thousands of patients in the United States (U.S.). Fortunately, almost all patients in the U.S. have access to payment structures for dialysis, transplantation, and immunosuppressants utilizing a combination of private and government-funded mechanisms. Nonetheless, while the healthcare system provides substantial support, especially through federally provided Medicare, financial barriers still limit access to kidney transplantation. These barriers particularly affect living donors, whose contributions to saving lives remain underappreciated and under protected by the current US-based healthcare payment structures. This article delves into the current landscape of ESRD treatment financing in the U.S., the challenges living donors face, and the legislative efforts aimed at improving support for donors.

### The Current State of Health Coverage for Kidney Transplants in the U.S.

With approximately 786,000 patients currently undergoing dialysis and around 90,000 awaiting a kidney transplant, ESRD poses a significant public health challenge in the U.S.<sup>(1)</sup> Kidney transplants account for 86% of all organ transplants in the country, with the average cost of about \$150,000 per procedure and annual post-operative care amounting to over \$30,000.<sup>(2)</sup> Dialysis itself costs approximately \$100,000 per patient annually for the patients on Medicare, while commercial insurance pays \$20,000-30,000 per month for dialysis and associated ESRD-related co-morbidity costs, making ESRD one of the most expensive chronic conditions to treat. Medicare alone spends more than \$35 billion annually, 7% of total Medicare spending, on the management of ESRD patients, even though these patients comprise only 1% of all Medicare patients.<sup>(3)</sup>

In terms of coverage, U.S. patients typically rely on either public insurance programs such as Medicare, Medicaid, TRICARE, and the Veteran's Administration, or private insurance through employers or the Affordable Care Act. Medicare provides coverage for individuals over 65 and those with disabilities, ALS, or ESRD,

making it a critical safety net for kidney transplant patients. The Medicare End Stage Renal Disease Program, signed into law by Richard Nixon in 1972, is one of the few disease-specific entitlement programs of the US government. For individuals with ESRD under 65, Medicare covers costs only after 33 months, during which private insurance serves as the primary payer. During this time, Medicare covers 80% of what private insurance does not pay, and the remaining 20% is borne by the patient. Once Medicare assumes primary responsibility, the roles switch with Medicare paying the first 80% of the cost and private insurance covering the remaining costs, while the patient continues to pay out of pocket costs (also called a "co-pay"). These out-of-pocket costs are capped annually so that the patient is not burdened extraordinarily, after which all the costs are borne by private insurance and/or Medicare.

Approximately 97% of both living and deceased donor kidney transplants in the U.S. are covered by a combination of Medicare (57%), Medicaid (8%), and commercial insurance (33%).

The long wait times for deceased donor transplants, typically - 5 years, mean that the majority - around 70% - of these transplants are covered by Medicare or Medicaid. In contrast, recipients of living donor kidney transplants experience significantly shorter wait times, so most of these transplants (55%) are covered by commercial insurance, though Medicare and Medicaid still account for 43% of coverage in these cases.

In January 2023, Medicare extended lifetime coverage of immunosuppressive drugs for kidney transplant recipients, whose transplants were covered by Medicare but could not secure alternate insurance support, removing the previous 36-month limit.

### Challenges for Living Donors

Living donors are essential to the success of kidney transplants, providing better outcomes than deceased donor transplants and offering recipients the chance to avoid long waiting times. However, living donors often face financial burdens that are not fully covered





## Health Coverage for Kidney Transplants in the U.S.

by insurance. While recipient insurance typically covers the donor's surgery and immediate medical expenses, complications that arise more than 90 days after donation are covered by Medicare but may not be covered by private insurance. Transplant centers often negotiate with insurers or absorb these costs to protect donors from financial hardship.

Beyond the medical costs of the evaluation, surgery, hospitalization, and follow-up for living kidney donation covered by recipient's healthcare payer, donors face additional financial challenges that have been estimated to exceed \$4,000 per donation.<sup>(4,5)</sup> Unfortunately, living donors must still take time off of work and often incur lost wages, travel expenses, and child/elder care costs. Despite the altruism inherent in donation, these financial barriers can deter potential donors, exacerbating the ongoing organ shortage.

### The Living Donor Protection Act and Donor Protection Programs

The proposed Living Donor Protection Act represents a crucial step toward addressing the financial and insurance challenges faced by living donors. Programs like the National Living Donor Assistance Center (NLDAC) provide financial support for donors with recipients

below the poverty line, and organizations like the Alliance for Paired Kidney Donation (APKD) and the National Kidney Registry (NKR) offer assistance for out-of-pocket costs to donors involved in paired exchanges.

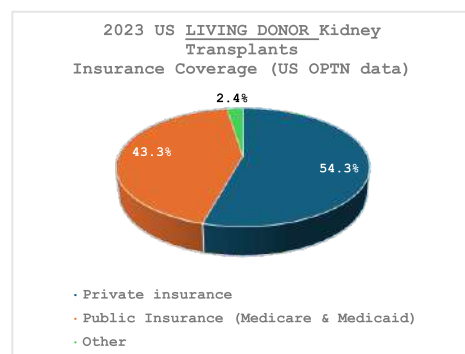
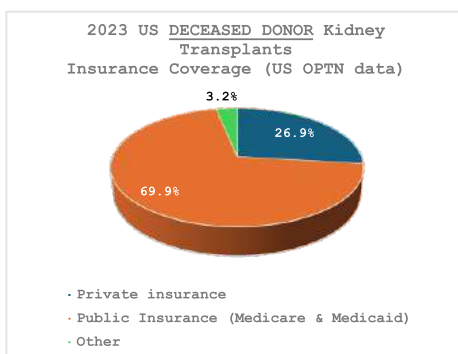
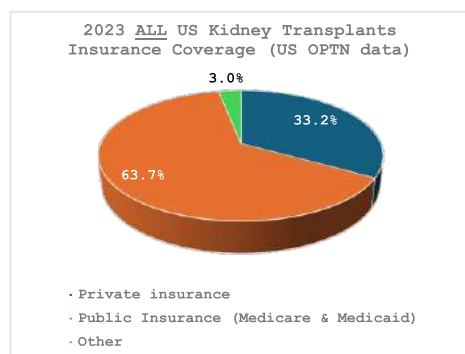
### Conclusion

While payment structures provide coverage for almost all US citizens with ESRD, challenges remain to overcome financial barriers that prevent some living kidney donations.

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**To cite :** Agnihotri A. Health Coverage for Kidney Transplants in the U.S. *Indian Transplant Newsletter*. 2024 Jul-Sep; 23(3):p8-9.



### Contributors



**Betty Crandall**  
APKD, Director, Transplant Center Administrative Relationships

Betty Crandall, MS, RN, is an experienced transplant administrator. During her nearly 30 years in the field of organ transplantation, Betty has worked with three transplant programs: The Johns Hopkins Comprehensive Transplant Center in Baltimore; Sentara Transplant Center in Norfolk, Virginia; and most recently, Wake Forest Baptist Medical Center in Winston-Salem, North Carolina. Additionally, she's assisted transplant programs throughout the country as an independent consultant or on a peer review committee and served on numerous committees for the United Network for Organ Sharing and the Organ Procurement and Transplantation Network. Currently, Betty helps APKD foster and build relationships with transplant centers across the United States.



**Prof. Michael A. Rees, MD, PhD**  
CEO, APKD

Together with his father, a computer programmer, Mike designed the first prototype of a computer program that matched willing but incompatible kidney donor and recipient pairs. Six years later, in 2006, he helped found the Alliance for Paired Kidney Donation, a globally renowned organization that manages an industry-leading kidney registry.

In addition to his role with the APKD, Mike serves as a professor in the Department of Urology, the Director of Renal Transplantation and transplant surgeon at the University of Toledo Medical Center.

Mike earned his medical degree from the University of Michigan then completed a three-year fellowship in transplantation at the University of Cambridge, where he completed research for a PhD in immunology.

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



**Dr. Ankur Mittal**  
Additional Professor & Head  
Department of Urology  
AIIMS, Rishikesh

**AIIMS Rishikesh recently had its first deceased organ donation. This is a remarkable achievement. Can you tell us more about it?**

Yes, AIIMS Rishikesh reached a major milestone with its first deceased organ donation on August 1, 2024. The donor was a 25-year-old young man, a pilgrim from Haryana who had been involved in a tragic road accident while bringing Ganga water from Haridwar. After being declared brainstem dead at AIIMS Rishikesh, his family made a brave and

compassionate decision to donate his organs, offering a second chance at life to many others. His one kidney and pancreas were sent to PGIMER Chandigarh, while the other kidney and liver were shared with ILBS, Delhi. Both corneas were used at the AIIMS Rishikesh eye bank.

**AIIMS Rishikesh is the first government hospital in Uttarakhand to initiate living renal transplants, which is a significant achievement. Can you tell us about this journey?**

AIIMS Rishikesh has become the first government hospital in Uttarakhand to successfully initiate living renal transplants, marking a major advancement in healthcare for the region. So far, the institute has completed 8 live-related renal transplants, under the guidance of a team from AIIMS Delhi. This milestone has brought new hope to patients with end-stage renal disease in the region and lays the groundwork for further expansion of transplant services at AIIMS Rishikesh.

**Are there other transplant centers in Uttarakhand?**

Yes, besides AIIMS Rishikesh, there are three other operational transplant centres in Uttarakhand, located in Dehradun: Max Hospital, Himalayan Institute of Medical Sciences (HIMS), and Shri Guru Ram Rai Institute of Medical & Health Sciences (SGRRIMHS). While these centres play a vital role in expanding access to transplantation services in the region, providing patients with more opportunities for life-saving treatments like kidney transplants, AIIMS Rishikesh is the only public hospital in this region that is performing transplants.

**What efforts are underway to promote organ donation in the region?**

Several initiatives are being taken to promote organ donation in the region. AIIMS Rishikesh has partnered with the NGO, MOHAN Foundation to drive campaigns both online and offline, focussing on deceased organ donation. As part of this partnership, regular organ donation awareness sessions are conducted to educate people, dispel myths, and encourage donor registration. Public outreach efforts, including social media, local TV, radio, and newspapers, highlight real-life success stories, while community and religious leaders are engaged to promote cultural acceptance of organ donation. The institute's medical staff are being trained to identify and manage potential donors, ensuring a smooth donation and transplant process.

**What do you see as the main challenges for organ donation and transplantation in Uttarakhand?**

There are several key challenges for organ donation and transplantation in Uttarakhand. Public awareness remains limited despite ongoing efforts, with myths, religious beliefs, and misconceptions discouraging many from registering as donors.

The healthcare infrastructure, while improving, is still developing, especially in remote areas, affecting organ retrieval, preservation, and transplantation capabilities. Coordinating organ retrieval and timely allocation is also a logistical challenge due to the region's difficult terrain, often resulting in delays or missed opportunities.

Additionally, there is a shortage of trained transplant coordinators and specialized healthcare professionals to manage donor identification and organ retrieval.

**And opportunities?**

I feel that expanding public awareness campaigns, including the involvement of influential individuals, religious leaders, and government initiatives, can shift perceptions and encourage more people to register as organ donors.

Strengthening and increasing the number of transplant centers in the region would reduce reliance on out-of-state facilities and better serve the local population. Training healthcare professionals, such as surgeons, coordinators, and nurses, is essential for improving the efficiency of the donation and transplantation process.

Government support through favourable policies and funding would enhance infrastructure, awareness efforts, and organ donation drives. Additionally, the region offers potential for research on organ transplantation and donation trends, which could lead to innovative solutions tailored to the unique demographic and geographical challenges of Uttarakhand.

**Any other thoughts before we close?**

The seamless coordination by the multi disciplinary team at AIIMS Rishikesh, under the leadership of our Executive director and CEO Prof Meenu Singh, supported by the National Organ and Tissue Transplant Organization (NOTTO) and ROTTO, ensured the donation process was carried out efficiently and with deep respect for both the donor and his family.

The donor's legacy lives on through the lives he saved, and this first donation serves as a powerful example for the region, further advancing AIIMS Rishikesh's mission to promote organ donation in Uttarakhand and beyond.

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

To cite : Mittal A, Kumar P. Uttarakhand - An Emerging State's Experience with Deceased Organ Donation. Indian Transplant Newsletter. 2024 Jul-Sep; 23(3):p10.



## 'Chintan Shivir' - Advancing Organ Donation and Transplantation in India

India's Union Health Ministry, through the apex body for Organ donation and transplantation, NOTTO (National Organ and Tissue Transplant Organization), held 'Chintan Shivir' - a brainstorming session to bring about reforms for augmentation of organ and tissue donation and transplantation with respect to Technology, Processes and Legislations in India.

Ten subjects (mentioned below) were identified and a working group for each subject was formed. These groups met thrice virtually, and discussed extensively, while involving external stakeholders, as required. The lead person of each group summarised the discussion points and presented at the 2-day 'Chintan Shivir' hosted by NOTTO at NCVDC building, New Delhi, on August 30-31, 2024.

This was a commendable initiative that fostered meaningful discussions, involving important stakeholders – healthcare

professionals and policymakers, facilitating comprehensive dialogues on improving organ donation practices. The Shivir underscored the need for a unified approach to address the persistent issues in organ transplantation, including disparities in access, loopholes in the current law, pain points of donors and recipients, and the need for greater public engagement through NGO involvement.

The Chintan Shivir inaugural was presided by Ms. L.S. Changsan, Additional Secretary, Ministry of Health and Family Welfare (MoHFW), Govt. of India, Prof. (Dr.) Atul Goel, DGHS, GOI, Shri Apurva Chandra, Secretary (MoHFW), GOI and Dr. Vandana Jain, Joint Secretary (MoHFW), GOI. "Organ donation needs to become a way of life for us so that we can give a new lease of life to those suffering from organ failure", said Ms. L. S. Changsan, stressing the importance of need for policies and systems to be conducive to organ donation and transplantation.

### Ten Subjects Discussed by the Working Groups at the 'Chintan Shivir'

#### GROUP 1 - Ensuring transparency in organ sharing for optimal use

- Registration of recipient – Identifying & correcting gaps
- Possibility of a digital dashboard for organ and recipient availability
- Way forward

#### GROUP 2 - One Nation One Policy: Issues and challenges

- One Nation, One portal: Single Digital registry
- Uniform allocation policy
- Permissible state-wise modifications in organ specific policy and criteria

#### GROUP 3 - Plugging legal loopholes

- Strengthening laws and their enforcement by authorities
- Increasing powers of NOTTO
- Punitive actions against defaulters
- Implications w.r.t eye, blood and tissues for research

#### GROUP 4 - Recent directives in Court Judgements

- Avoiding court cases in matters of organ donation
- Donation from minor living donors
- NOTTO Foundation (possibility and roles)
- NGO's perspectives (roles and responsibilities)

#### GROUP 5 - Improving transplant outcomes

- Experience from the past 25 years
- Optimising outcomes
- Alternative systems and their role in improving outcomes

#### GROUP 6 - Death related issues

- Uniform definition of death - challenges
- Difficulties in declaring Brainstem death - battling the perceptions
- Controversy surrounding BSD - Bioethical issues and way forward
- Donation after circulatory death

#### GROUP 7 - Correcting the ecosystem

- Organ retrieval centres in each medical college
- Training in organ retrieval
- Retrieval policy targeting zero loss of eligible donor
- Maximization of organ utilisation

#### GROUP 8 - Health insurance issues in organ transplantation

- Insurance related issues of donors and recipients in India
- Current status and future directions
- Health protection of Living donors – whose responsibility?
- Role and responsibility of IRDA

#### GROUP 9 - Bottlenecks, solutions and future of organ transplantation

- Identifying the problems
- Learning from mistakes
- Learning from each other
- Best practices
- Threat of Anti-microbial Resistance (AMR) with respect to future of organ transplant
- Adoptive cell transfer or Cell/organoids from Stem cells - Future possibilities
- Likely bioethical issues

#### GROUP 10 - Community participation and social mobilisation for augmenting awareness on organ donation and prevention

- Views of stakeholders on augmenting awareness on Brain death and donation
- Alternative medicine and their role in prevention
- The case for Prevention – Role of NOTTOs and NGOs

This initiative, 'Chintan Shivir' by NOTTO, exemplified a proactive step towards strengthening India's organ donation framework, aiming to save more lives through increased collaboration, awareness, and improved systems. It was a significant event that not only recognized the existing challenges but also celebrated the collective efforts of all involved in the noble cause of organ donation.

**To cite :** Jairam J. 'Chintan Shivir' - Advancing Organ Donation and Transplantation in India. Indian Transplant Newsletter. 2024 Jul-Sep; 23(3):p11.



## NGOs 5<sup>th</sup> Collaborative Conclave for Organ Donation



**Ms. Sunayana Singh**  
Chief Executive Officer  
Organ India

The 5<sup>th</sup> Collaborative Conclave on Organ Donation for NGOs and government bodies took place on August 4, 2024 at the India Habitat Centre in New Delhi. ORGAN India, Parashar Foundation, under the aegis of National Organ & Tissue Transplant Organization (NOTTO), organised this annual event, where national, regional, and non-government stakeholders convened under one umbrella to discuss critical issues, challenges, and potential solutions within the organ donation ecosystem. The

Conclave saw participation from 16 NGOs and key stakeholders, including NOTTO, ROTTO North, ROTTO/SOTTO West, SOTTO MP, SOTTO J&K, ZTCC Pune, the Appropriate Authority of Rajasthan, Vidhi Center for Legal Policy as well as members of India's Transplant Sports Team.

The Conclave was inaugurated by the Chief Guest, Prof. (Dr.) Atul Goel, Director General of Health Services, MoHFW, GOI, who stressed that NGOs must put a lot more focus on prevention of organ failure as there will never be enough organs to meet the demand.

The NGOs present were ORGAN India (Delhi), MOHAN Foundation (pan India), Zuble Foundation (Assam), Shine India Foundation (Rajasthan), Donate Life (Gujarat), Kidney Warriors Foundation (Maharashtra), Kidney Patient Welfare Foundation (Rajasthan), Barasat Samajik Pratishthan (West Bengal), Bengal Organ Donation Society (West Bengal), Dadhichi Deh Daan Society (Delhi), MFJCF (Rajasthan), Kiran Foundation (Karnataka), Komal New Life Foundation (Maharashtra), Rebirth Foundation (Tamil Nadu), Shatayu (Gujarat), Bhartiya Jan Sangh (Delhi). Each NGO presented its work, highlighted unique activities that could serve as models for other organizations, and shared the challenges they face in the field. The Conclave included the following panel discussions:

1. Advisory Committees & the Role of NGOs in Aiding NOTTO, ROTTO, SOTTO.
2. Pan India Body Donation - Facilitating Body Donation through NGOs.
3. Transplant Games in India & Abroad - Promoting Health and Raising Awareness.



Discussion groups were formed which focused on technology, process, and legal reforms to establish a more transparent National Policy on Organ Donation and Transplantation. Below are some of the key recommendations:

1. One Nation, One Policy: Issues and Challenges
  - The government shall bear the cost of transporting organs across states to ensure equitable allocation.
  - States adopting NOTTO's guidelines to standardize organ allocation.
  - Recognize and motivate NTORCs to promote organ donation.
  - Donor families should be honoured, and organ donors / transplant recipients should serve as brand ambassadors to promote post-transplant health and inspire others.
2. Amendments to the Law: Living Donor Protection Act
  - Hospitals must update registries, with penalties and license suspensions for violators.
  - Guidelines for authorizing committees and transplant hospital donations should be set by NOTTO, with a minimum number of donations required for license renewal.
3. Community Participation and Social Mobilization
  - NGOs and government should collaborate on donor family felicitation and support.
  - Donor families could receive benefits like government jobs, health insurance, or education for children.
  - Public and medical awareness campaigns are crucial for promoting organ donation.
  - NOTTO should issue advisories to verify NGOs in each state to facilitate easier collaboration and outreach.
4. NGO Roles and Responsibilities
  - NGOs should maintain ethics, confidentiality, and compliance with laws, and collaborate with the government.
  - Correct information dissemination, staff training, and support for donors/recipients should be prioritized.
  - NGO credibility endorsed by NOTTO/ROTTOT/SOTTO
5. Health Insurance for Donors and Recipients
  - IRDA should create favourable insurance products for donors and recipients.
  - Expand coverage to all organ transplants, like Ayushman scheme.
  - Living donors should receive insurance as they are medically fit when donating.
6. Successes and Challenges from New States
  - Dialogue with state governments is lacking in the Northeast region, and NGOs struggle with credibility for community education programs, especially among tribal communities with strong cultural beliefs regarding the deceased.

**To cite :** Singh S.A. NGOs 5<sup>th</sup> Collaborative Conclave for Organ Donation. Indian Transplant Newsletter. 2024 Jul-Sep; 23(3):p12.



## Observance of the 14<sup>th</sup> National Organ Donation Day

The 14th National Organ Donation Day was observed at the Dr. Ambedkar International Centre on August 3, 2024. To commemorate the occasion, NOTTO, under the Ministry of Health and Family Welfare, organized the celebration program in New Delhi. Ms. Anupriya Patel, Minister of State for Health and Family Welfare, was the chief guest, and Dr. Vinod K. Paul, a Member (Health) of NITI Aayog, was the guest of honour. Dr. Atul Goel, Director General of Health Services, and Dr. Anil Kumar, Director of NOTTO, were the hosts for the event.

The event was also attended by Mr. Apurva Chandra, Secretary of the Ministry of Health and Family Welfare, along with senior doctors from various states and medical institutions.

Indian Organ Donation Day has been observed annually since 2010. Its purpose is to raise awareness about brain stem death and organ donation, dispel myths and misconceptions, and encourage citizens to donate organs and tissues after death.

Ms. Patel felicitated deceased donor families and recognized organ recipients and doctors nationwide for their remarkable contributions to transplant medicine. Addressing the occasion, she

noted that the organ donation rate has quadrupled to 18,378 over the past decade, praising the efforts of both doctors and donor families for their life-saving decisions. She lauded the family members of deceased organ donors for "doing the greatest service to mankind by saving the lives of numerous people." Calling them an inspiration for the entire country, she encouraged citizens to pledge to donate their organs after death. "It is only through the concerted efforts of every individual and institution that India can realize its vision of becoming one of the leading countries in organ donation and transplantation," she said.



## Recognizing Remarkable Contributions to Organ Donation and Transplant Medicine

ROTO / SOTTO	HOSPITALS	SOCIETIES / NGOs	INDIVIDUALS
<p><b>Best ROTTO</b></p> <ul style="list-style-type: none"> <li>ROTO North - Post Graduate Institute of Medical Education &amp; Research (PGIMER) Chandigarh</li> </ul> <p><b>Best SOTTO</b></p> <ul style="list-style-type: none"> <li>1st - Telangana</li> <li>2nd - Tamil Nadu &amp; Karnataka</li> </ul> <p><b>Best Emerging State - Northeast</b></p> <ul style="list-style-type: none"> <li>Manipur</li> </ul> <p><b>Emerging States in Organ Donation</b></p> <ul style="list-style-type: none"> <li>Andhra Pradesh</li> <li>Madhya Pradesh</li> <li>Jammu &amp; Kashmir (J&amp;K)</li> </ul> <p><b>State with Best Awareness / Information, Education &amp; Communication (IEC) activities</b></p> <ul style="list-style-type: none"> <li>Rajasthan</li> </ul>	<p><b>Best NTORC</b></p> <ul style="list-style-type: none"> <li>Civil Hospital, Ahmedabad</li> </ul> <p><b>Emerging NTORC</b></p> <ul style="list-style-type: none"> <li>Command Hospital, Chandimandir</li> <li>Dr. Rajendra Prasad Government Medical College, Kangra</li> </ul> <p><b>Best Hospital (Private) with Highest Deceased Donation</b></p> <ul style="list-style-type: none"> <li>Yashoda Hospital, Secunderabad</li> </ul> <p><b>Efficient Revival of the Deceased Organ Donation Program</b></p> <ul style="list-style-type: none"> <li>Government: Safdarjung Hospital, New Delhi</li> <li>Private: KEM Hospital, Mumbai</li> </ul> <p><b>Best Brainstem Death Certifying Team (Region wise)</b></p> <ul style="list-style-type: none"> <li>West - New Civil Hospital, Surat</li> <li>North - JPN Apex Trauma Centre, AIIMS, New Delhi</li> <li>South - KIMS, Secunderabad</li> <li>East - IPGMER, Kolkata</li> </ul> <p><b>Active Lung Transplant Centre North India</b></p> <ul style="list-style-type: none"> <li>Medanta The Medicity, Gurugram</li> </ul>	<p><b>Best Supportive Societies</b></p> <ul style="list-style-type: none"> <li>Army Organ Retrieval &amp; Transplant Organization (AORTA)</li> <li>Times of India (TOI)</li> <li>Indian Society of Organ Transplantation (ISOT)</li> <li>Indian Society of Critical Care Medicine (ISCCM)</li> <li>Liver Transplant Society of India (LTSI)</li> <li>Indian Medical Association (IMA)</li> <li>Delhi Police</li> </ul> <p><b>Best Supportive NGOs</b></p> <ul style="list-style-type: none"> <li>Liver Foundation of Kerala, Ernakulam</li> <li>Barasat Samajik Seba Pratisthan, Kolkata</li> <li>ORGAN India, Delhi</li> <li>Rebirth Foundation, Pune</li> <li>Donate Life, Surat</li> <li>Dadhichi Deh Daan Samiti, Delhi</li> <li>MOHAN Foundation - Jaipur Citizen Forum (MFJCF)</li> <li>Bhartiya Jain Sanghatana (BJS), Delhi</li> </ul>	<p><b>Lifetime Achievement Award</b></p> <ul style="list-style-type: none"> <li>Dr S K Mathur</li> </ul> <p><b>Exemplary Award</b></p> <ul style="list-style-type: none"> <li>Dr Pranjal Modi, IKDRC, Ahmedabad</li> <li>Dr Subhash Gupta, Max Healthcare, Delhi</li> <li>Dr Viniyendra Pamecha, ILBS, Delhi</li> </ul> <p><b>Best Transplant Coordinator</b></p> <ul style="list-style-type: none"> <li>Mr Ponraj, RGGGH, Chennai</li> <li>Dr Ketan Naik, New Civil Hospital, Surat</li> <li>Lt Col Chetna Sharma, Army Hospital R &amp; R, Delhi</li> </ul> <p><b>Women Pioneer in the Field of Organ Transplant</b></p> <ul style="list-style-type: none"> <li>Dr Swarnalatha, Jeevandan, Telangana</li> </ul> <p><b>Promoting Ethical Transplant</b></p> <ul style="list-style-type: none"> <li>Dr Sanjay Nagral, Mumbai</li> </ul> <p><b>Transplant Professional Promoting India at International Fora</b></p> <ul style="list-style-type: none"> <li>Dr Vivek Kute, Ahmedabad</li> </ul>

To cite : Sahi M K. Observance of the 14<sup>th</sup> National Organ Donation Day. Indian Transplant Newsletter. 2024 Jul-Sep; 23(3):p13.



## Research-Based Lessons: Barriers and Solutions to Deceased Donation



**Dr. Britzer Paul V**  
University of Bedfordshire

Dr. Britzer Paul's PhD research was on identifying the barriers and facilitators influencing deceased organ donation in India, focussing on both the public and the key stakeholders. This PhD research was conducted in collaboration between the University of Bedfordshire, United Kingdom, and the MOHAN Foundation, India, supported by a full scholarship under the Global Challenges Research Fund (GCRF).

**Methods:** The research comprised a systematic review and two qualitative studies. The integrative systematic review (Study 1) revealed that decisions regarding organ donation are shaped by multiple societal layers, influenced by an individual's socialisation process. Consequently, Studies 2 and 3 were guided by the socio-ecological model and social constructivist philosophy, employing a qualitative approach. These studies were conducted in Chennai, Chandigarh, and Delhi (India). Study 2 involved 25 focus group discussions with the general public, while Study 3 comprised 14 in-depth interviews with transplant coordinators involved in facilitating deceased organ donations in these regions. Data from both the studies were analysed using framework analysis, which facilitated comparison of cases to identify similarities and differences. This approach was particularly useful for comparing public attitudes and stakeholder experiences in regions with differing levels of deceased organ donation performance.

**Findings:** The three studies collectively highlighted that while individuals may express a willingness to become organ donors, their decision-making is often influenced by external societal factors, including family, religion, community, and trust in the healthcare system. In many cases, an individual's intention to donate is overridden by the larger social context, particularly when the final decision rests with family members, as is the case in India's opt-in policy. Even though individuals may discuss various aspects of life openly with their families, they tend to avoid sensitive topics such as death and deceased organ donation, fearing resistance or disapproval. While religion was identified as a barrier in the systematic review, the qualitative research suggested that uncertainty surrounding religious perspectives rather than explicit religious opposition contributed to hesitation in registering or consenting to organ donation. Additionally, the negative portrayal of deceased organ donation in social media and community conversations fostered mistrust in the healthcare system, further discouraging individuals from donating. There was also a perceived inequity in access to transplants, leading people to question why they should donate organs when they themselves might not receive one in need. Although these barriers were prevalent across all study sites, significant differences emerged in the healthcare system's practices and infrastructure.

**To cite :** Britzer Paul V. Research-Based Lessons: Barriers and Solutions to Deceased Donation. Indian Transplant Newsletter. 2024 Jul-Sep; 23(3):p14.

The interviews with transplant coordinators revealed that the availability of infrastructural support had a substantial impact on consent rates. Factors such as accountability, organisational support (from government bodies, the police, and hospitals), and institutional policies and practices were crucial. Centres with robust infrastructure, policies, and practices achieved higher rates of deceased organ donation compared to those lacking these supports. This underscores the need to focus not only on public awareness and engagement but also on hospital practices to improve organ donation outcomes. Learning from high-performing centres and implementing consistent policies and practices across all regions are essential steps toward enhancing deceased organ donation rates and achieving self-sufficiency in India.



Dr. Britzer Paul with  
Prof. Gurch Randhawa  
Prof. of Diversity in Public Health  
University of Bedfordshire

Countries like Spain have demonstrated the importance of strengthening hospital networks and infrastructure, while others have emphasised community engagement. In the context of India, a dual approach, incorporating both strategies, could prove effective. Addressing the barriers and facilitators identified in the current study in improving hospital-level practices and standardising deceased organ donation procedures across regions along with community engagement in normalising conversations about deceased organ donation would foster a more supportive environment for deceased organ donation in India. This PhD research, therefore, advocates for a whole-systems approach to improving deceased organ donation in India.



Community engagement with Muslim community in the UK

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## Young Changemakers

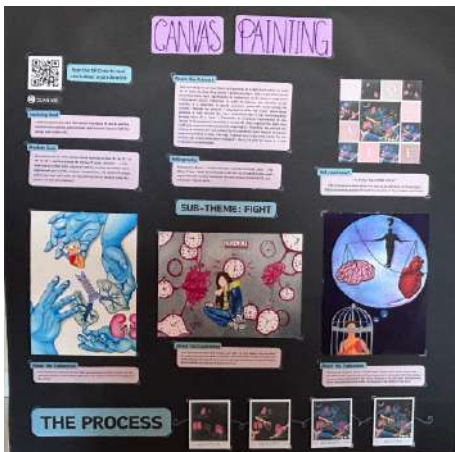
Riyaa Palan



Riyaa with her Painting on Organ Donation

I've been an organ donation ambassador with MOHAN Foundation since 2022 and since then, I have conducted various awareness sessions for the teachers and parents of my school community as well as for corporate businesses such as Schindler India. Apart from this, I undertook a 6-month long art project to raise awareness about organ donation and during the summer, I also worked on a research project with the Foundation (about the extent of insurance access available to transplant recipients and organ donors in India). Currently, I'm working on a fundraising project for MOHAN Foundation's initiative Anudaan to help sponsor a part of the surgery fee for a nine-month-old infant's liver transplant.

Through these experiences, I have been able to further strengthen my bond with the cause and I hope that our collective efforts can together lead India to be a leading organ donation hub in the world where this cause is not looked down upon but instead, honoured and celebrated - Put simply, I hope that someday, everyone in this country and around the world can appreciate the 'Gift of Life' for what it truly is.



Krishna Toshniwal



My name is Krishna Toshniwal, and my journey with MOHAN Foundation began when I interned with them. During that time, I saw firsthand the beautiful cause they work towards - the life-saving impact of organ donation. I was deeply moved by the stories and data showing how one donor can transform the lives of many people in need. This experience has motivated me to support the foundation in every way, I can.

To raise both funds and awareness, I've been selling Eco-Friendly Ganesh idols for the past four years, with all profits going towards MOHAN Foundation. Knowing that my efforts can contribute to such a meaningful cause gives me immense joy. The work they do has inspired me, and I am honoured to play a small role in their mission to save lives.



Krishna at MOHAN Foundation's Event

To cite : Kanvinde H, Kumar P. Young Changemakers. Indian Transplant Newsletter. 2024 Jul-Sep; 23(3):p15.

Jason Moses



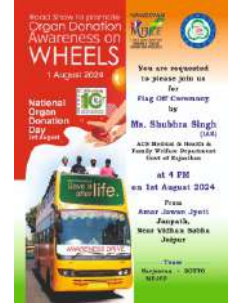
I'm Jason, a 16 year-old runner and homeschooler from Delhi. I'm excited to be running my first half marathon this year at VDHM ( Vedanta Delhi Half Marathon) on October 20, 2024 in Delhi. I want to make it extra special by raising funds and supporting a life saving mission.

Today, I am privileged to be in good health. What better way to give back to society than to help those who don't have this privilege? 'Anudaan', by MOHAN Foundation, is raising funds to make a difference in supporting organ transplantation especially for children. As a child, this is a cause very close to my heart. I am grateful to have the opportunity to help others. Together, we can make the world a better place for children through 'Anudaan'.



# Public Awareness Campaigns

## WHEELS - Road Show to Promote Organ Donation Awareness (August 1, 2024)



## Public Structures Illuminated in Green to Promote Organ Donation (August 3, 2024)



Ripon Building, Chennai



Atal Setu, Goa



Albert Hall Museum, Jaipur

## TAMIL NADU 10K RUN - Run for Organ Donation Awareness (August 4, 2024)



## ANUDAAN : Making Transplants Affordable

**अनुDAAN**  
Making Transplants Affordable

An initiative to raise funds for underprivileged patients to enable them to undergo life-saving transplants.

With support from other like-minded NGOs, corporates and philanthropic individuals



6 year old Aaradhya underwent a liver transplant on January 16, 2021 thanks to efforts made by Anudaan



SCAN HERE

TO READ ABOUT PATIENTS WE HAVE HELPED