

INDIAN TRANSPLANT

NEWSLETTER

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MULTI ORGAN HARVESTING AID NETWORK

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Editorial Desk**Contribution of MOHAN Foundation to SDG 3**

In a landmark meeting in 2015, all member nations of the UN adopted an Agenda for Sustainable Development for 2030, aiming to create peace and prosperity for people and the planet. This agenda is guided by 17 Sustainable Development Goals (SDGs), which recognize that action in one area affects outcomes in others, and that development must balance social, economic, and environmental sustainability.

Goal 3 aims to ensure healthy lives and promote well-being for all, at all ages. It seeks to address global improvements in maternal health for women and babies, increase life expectancy for all, and reduce some of the most common and preventable causes of death. This goal also addresses all major health priorities: child and adolescent health, communicable and non-communicable diseases, universal health coverage, and access to safe, effective, quality, and affordable medicines and vaccines for all.

MOHAN Foundation began its journey in 1997, engaging the public in understanding the concepts and nuances of organ donation. In its 27 years of existence, more than 25 million people have been educated and sensitized about organ donation, and over 81,000 have pledged as donors on their online donor registry.

Despite these efforts, the rate of donation still does not meet the need for organs required. The presence of a trained grief counsellor can support families in making decisions about organ donation in ICU hospital settings. Training such healthcare specialists has been a key factor in the increase of deceased donations in the country. MOHAN Foundation has trained 4051 grief counsellors and transplant coordinators (December 2009 - June 2024), who now work in almost 60% to 70% of the transplanting hospitals in India.

Setting up processes and establishing local protocols in government hospitals to start both living and deceased donations and transplantation has been another significant contribution of MOHAN Foundation towards achieving SDG 3 goals. Examples include states like Tamil Nadu, Andhra Pradesh, Kerala, Rajasthan, and Manipur. In 1998, only Four states and Union Territory in India which included Tamil Nadu, Delhi, Karnataka, and Maharashtra - were somewhat successful in conducting deceased donations. By 2022, 26 States and Union Territories in India had begun performing transplants.

MOHAN Foundation has been instrumental in advocating for ethical deceased donation and transplantation, thus fulfilling a major goal of Sustainable Development. Their continuous efforts have made a significant impact on improving health outcomes and saving lives, aligning with the objectives of SDG 3.

Read more about SDG and organ donation on page 11.

To cite : A S Sher, Shroff S. Contribution of MOHAN Foundation to SDG 3. Indian Transplant Newsletter. 2024 Apr-Jun; 23(2):p1.

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Spain Achieves A New Benchmark with 48 Organ Transplants in a 24-Hour Period

On April 17, 2024, amidst the tragic loss of their loved ones, 17 families made the selfless decision to donate their loved ones' organs. Additionally, two individuals donated living organs on the same day. In total, 19 donors contributed within a single day, giving 48 patients the opportunity to save or to improve the quality of their lives. The National Transplant Organization (ONT) coordinated these efforts, with participation from 29 hospitals across eleven autonomous communities.

Of the 48 transplants performed, there were 25 kidney transplants, 11 liver transplants, seven lung transplants, three heart transplants, and two pancreas transplants. Among the transplant recipients were three children.

In 2023, Spain performed 5,863 organ transplants, achieving a rate of 122.1 transplants per million population. This was made possible by the 2,346 individuals who donated their organs after death, resulting in a donation rate of 48.9 donors per million population, and the 437 individuals who donated an organ while still alive.

To cite : Suriyamoorthi S, Shroff S. In the news. Spain Achieves A New Benchmark with 48 Organ Transplants in a 24-Hour Period. Indian Transplant Newsletter. 2024 Apr-Jun; 23(2):p2

Addendum: Xenotransplant-related news articles from earlier editions - According to the recent reports, all patients who had received genetically modified pig-to-human transplants in the United States have passed away.

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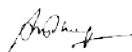
I, Sunil Shroff, hereby declare that the particulars given above are true to the best of my knowledge and belief.

Sd/-

Sunil Shroff

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Signature of Publisher



77th World Health Assembly - Delegates Approve Groundbreaking New Agreement on Transplantation

On 29 May 2024, Member States (with the initiation of Spain) approved a new resolution on increasing availability, ethical access and oversight of transplantation of human cells, tissues and organs.

Transplantation is a life-saving treatment. The latest data of 2022 from the Global Observatory on Donation and Transplantation indicate that more than 150 000 solid organ transplants ($\leq 10\%$ of global needs) are performed worldwide annually, which is an increase of 52% compared with 2010. However, there is still an apparent insufficient growth in and asymmetrical development of transplantation worldwide with many countries not having established the appropriate systems, including legislation, governance, specialized workforce, infrastructure and financing.

Lack of availability and equitable access to transplant may lead to death or unethical or illegal practices such as transplant tourism and organ trafficking. The resolution aims to improve availability of transplantation, especially in countries with limited resources.

The resolution aims to introduce measures to prevent and combat trafficking in people for the purpose of organ removal and trafficking in human organs, and to protect victims and survivors of these crimes by strengthening legislative frameworks.

Member States committed to take a set of actions including integrating donation and transplantation activities into health-care systems, so that deceased donation is routinely considered as an option at the end of life, and living donors are protected from exploitation and provided with proper follow-up care.

WHO is tasked to develop a global strategy on donation and transplantation, to be presented to the Assembly for adoption in 2026. WHO should also examine establishing a World Donor Day to raise public awareness and enhance understanding on the need for altruistic donation of human cells, tissues and organs.

To cite : <https://www.who.int/news/item/30-05-2024-seventy-seventh-world-health-assembly---daily-update--30-may-2024>



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Foreign Nationals must be Informed about India's Organ Transplant Regulations, says Union Health Ministry

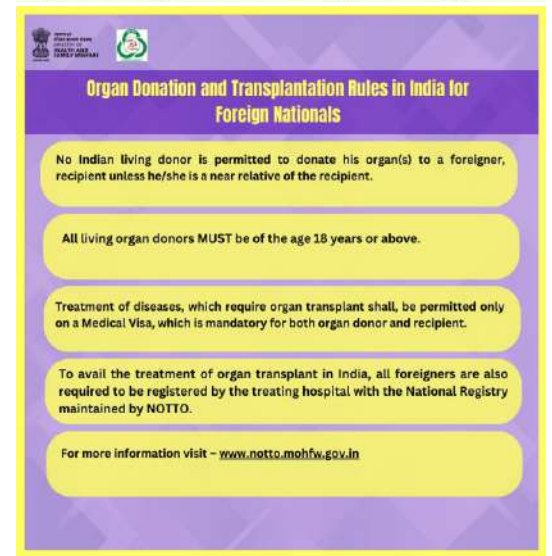
Union Health Ministry, in its communication in June 2024 to the Ministries of External Affairs and Home Affairs, highlighted the need to educate foreign nationals visiting India for organ transplants about the country's policies and regulations governing organ donation and transplant procedures.

India is becoming a leading destination for foreigners seeking organ transplants due to its world-class medical facilities and highly skilled medical professionals. Consequently, it is essential that these individuals are well-informed about the legal framework in India before undergoing such procedures.

It is recommended that the messages and materials provided by the Union Health Ministry be displayed on the websites and portals of the Ministry of Home Affairs' Bureau of Immigration, airports, and the websites of the Ministry of External Affairs, as well as Indian embassies and missions abroad, to ensure effective dissemination.

Before removing or transplanting human organs or tissues, foreign citizens travelling to India for living donor transplants must obtain approval from authorization committee constituted by the State or Centre. The relationship between the donor and recipient must be certified on the required form by a senior official from the embassy of the country of origin in India. If there is no embassy in India, the government of that country will issue the relationship certificate through a similar process.

Foreign nationals who require deceased donor transplants can also register in India through the hospital, and their information will be added to the waiting list. These situations, however, would only be taken into consideration for organ distribution if no suitable Indian patient was available nationwide.



To cite : Suriyamoorthi S, Shroff S. In the news. Foreign Nationals must be Informed about India's Organ Transplant Regulations, says Union Health Ministry. Indian Transplant Newsletter. 2024 Apr-Jun; 23(2):p3.

Tamil Nadu Sees Unprecedented Increase in Deceased Organ Donation

Tamil Nadu has seen an unprecedented surge in deceased organ donation in 2024, all within just four months. 102 deceased donations were facilitated in the State over a period of 130 days (January 1 - May 9, 2024). A total of 324 organs and 271 tissues retrieved from these donors were given to needy patients awaiting transplant. Additionally, two hand transplants have been performed this year. The Chief Minister's announcement in September 2023 that the deceased donors would receive State honours has been credited for reviving public interest in organ donation.

Ma Subramanian, Honourable Minister for Health and Family Welfare of Tamil Nadu declared, "It is mandatory for all government teaching medical college hospitals to declare brain death and

provide grief counselling. In the event that the hospitals are not authorized organ transplant facilities, they retrieve the organs with the approval of consenting families and distribute them, per TRANSTAN's (Transplant Authority of Tamil Nadu) directives, to a network of hospitals."

"Structured training programs were offered to medical professionals involved in deceased organ donation from government medical colleges," said Dr. N. Gopalakrishnan, Member Secretary of TRANSTAN.

To cite : Suriyamoorthi S, Shroff S. In the news. Tamil Nadu Sees Unprecedented Increase in Deceased Organ Donation. Indian Transplant Newsletter. 2024 Apr-Jun; 23(2):p3.

First Middle-East Organ Donation Course held in Dubai

The 1st Middle East Ataa Al Hayat Organ Donation Course was held from May 3-5, 2024, at MBRU (Mohammed Bin Rashid University) Dubai. This course is a collaborative effort of the National Center for Organ Donation and Transplantation (HAYAT), the Ministry of Health and Prevention (MOHAP), and Mohammed bin Rashid University (MBRU). Close to 60 ICU professionals (including intensivists, nurses, transplant coordinators) from healthcare authorities across the UAE and neighbouring countries participated in the course.

Ms Pallavi Kumar (Executive Director, MOHAN Foundation) was invited as course faculty. The invitation was extended by Dr. Ali Abdul Kareem Al Obaidli - Chairman of the National Committee for Organ Donation and Transplantation of the United Arab Emirates and Dr. Maria Paula Gomez, Director - Organ Transplant Expert, The National Center for Regulating Donation and Transplantation of Human Organs and Tissues, UAE Ministry of Health, and Prevention.

Ms Kumar made a presentation on "Attributes of a Coordinator - through case sharing - Lessons from MOHAN Foundation, India".

The two days program included the following workshops:

- Clinical Cases
- Donor detection and evaluation
- DNC declaration
- DBD Donor maintenance
- Family approach to organ donation



To cite : Kumar P. First Middle-East Organ Donation Course held in Dubai. Indian Transplant Newsletter. 2024 Apr-Jun; 23(2):p4

National Training for Transplant Coordinators held in Nepal

The Nepal Transplant Act, enacted to regulate and facilitate organ transplantation in the country, aims to ensure ethical practices, protect donors and recipients, and enhance the overall transplant ecosystem. Despite the legislative framework, there remains a critical need for skilled professionals to manage and coordinate transplant activities effectively. The recent amendments to the Human Body Organ Transplantation Act (HBOTA) in 2016 enabled brain death donations, marking a significant step forward. However, donation rates still remain low. The first national training for transplant coordinators, organised by the Shahid Dharmabhakta National Transplant Centre in collaboration with the MOHAN Foundation, addressed this need by equipping coordinators with the necessary knowledge and skills.

The two-day training held on June 24 - 25, 2024 was attended by 51 participants from 20 government and private transplant and teaching hospitals. The training encompassed an agenda tailored to the needs of the participants.

Ms. Pallavi Kumar (Executive Director, MOHAN Foundation, NCR) led the following sessions:

- A to Z of Organ Donation
- A no is not always a no
- Grief Counselling and making the Ask
- Implementing a Deceased Donation Programme in a Hospital

Dr. Muneet Kaur Sahi (Programme Manager, MOHAN Foundation, NCR) conducted the following sessions:

- Creating Public Awareness on Organ Donation
- Role of a Transplant Coordinator

Legal aspects of organ donation and transplant (HBOTA) Nepal was conducted by Mr. Harihar Pokhrel, Section Officer Member, Legal Committee, SDNTC, Nepal.

Apart from the sessions, many activities were undertaken that broke the monotony of the teaching sessions, bringing together all the participants in engaging discussions, networking opportunities, and practical exercises. A few of the activities that were conducted were: stakeholders' involvement, effective communication, and organ donation pathway.



To cite : Kumar P. National Training for Transplant Coordinators held in Nepal. Indian Transplant Newsletter. 2024 Apr-Jun; 23(2):p4.

Masterclass on Deceased Organ Donation, Belagavi

A three-day Masterclass on 'Deceased Organ Donation and Grief Counselling' was hosted by KLES Dr Prabhakar Kore Hospital & Medical Research Centre, Belagavi from April 10 to 12, 2024. This was conducted in association with MOHAN Foundation and supported by the SBI Foundation. 30 participants from different hospitals including public and private attended the workshop.

Deceased donor transplant - Legal framework

The session outlined brain death certification and documentation process, consent requirements, organ allocation guidelines, and penalties for any violations. The session also covered topics such as licensing requirements for conducting transplantations and deceased donations.

Approaching families for organ donation - The session addressed the delicate and challenging task of breaking bad news. The barriers, difficulties and the components involved in this challenging communication was discussed in detail. Approaching families for organ donation requires empathy and effective communication skills to navigate this sensitive conversation and respect for the family's needs and wishes.

Communication & Team building

The session emphasized the significance of effective communication, its essential elements and offering strategies to improve communication skills. Additionally, team building activities and initiatives were highlighted to underscore the value of collaboration, building team and strengthening relationships among team members.

The masterclass featured a variety of engaging activities, such as:

- Role-playing scenarios for counselling grieving families
- Deceased organ donation - Pathway
- Quiz on coordinating medico-legal cases



To cite : Suriyamoorthi S. Masterclass on Deceased Organ Donation and Grief Counselling, Belagavi. Indian Transplant Newsletter. 2024 Apr-Jun; 23(2):p5.

Masterclass on Soft Skills and Grief Counselling, Kolkata

MOHAN Foundation, in collaboration with the Bengal Organ Donation Society and NATCO, held a workshop on "Soft Skills & Grief Counselling" from May 22-23, 2024, at Narayana Health RTIICS Kolkata.

The workshop was attended by nearly 80 participants from various government and private hospitals from Kolkata as well as from other parts of the country. The workshop aimed to equip healthcare professionals with the knowledge and skills necessary to support organ donation and transplantation efforts effectively, emphasizing sensitivity, empathy, and comprehensive understanding of the processes and challenges involved. A few highlights from the workshop are:



Grief Counselling and Making the Ask

Techniques and approaches for counselling grieving families and sensitively broaching the subject of organ donation was discussed. "A NO is not always a NO" - An initial refusal for organ donation can get converted to a consent with appropriate communication strategies.



Importance of Grief Counselling in Deceased Organ Donation - An Intensivist Perspective: Insights from an intensivist on how grief counselling plays a crucial role in the context of deceased organ donation were discussed.

Roleplaying Scenarios: Participants engaged in simulated interactions with individuals who had experienced the loss of a loved one. These roleplaying scenarios allowed them to practice handling emotional and delicate discussions with greater sensitivity and empathy.

Communication and Body Language: Addressed the importance of effective communication and non-verbal cues in interactions with grieving families and colleagues.

The two-day workshop concluded with a certificate distribution ceremony, where Mr. Ahmed Hassan Imran, Chairman of the West Bengal Minorities Commission, presented certificates to the delegates.

To cite : Kumar P. Masterclass on Soft Skills and Grief Counselling, Kolkata. Indian Transplant Newsletter. 2024 Apr-Jun; 23(2):p5.

Metro Retro - Ramp Walk for a Cause

MOHAN Foundation celebrated 27 years of saving lives through a unique “METRO RETRO - RAMP WALK FOR A CAUSE” wherein luminaries from all walks of life walked the ramp at Ameerpet Metro Station, showcased their support for the cause of organ donation on June 15, 2024. This event was held in partnership with L&T Metro Rail, Hyderabad.

Prominent doctors, celebrities, transplant recipients, donor families and the MOHAN Foundation team from different parts of the country walked the ramp to create awareness about organ donation.

Popular Tollywood actor **Mr. Vishwak Sen**, was the Chief Guest at the event, and he pledged to donate organs. Mr. Vishwak Sen flashed his “Donor Card” and sincerely appealed to everyone to pledge for organ donation. He saluted all the transplant coordinators who spoke to the families during their darkest hour of grief.

Among the luminaries who walked the ramp was **Dr. Prashant Garg, Chairperson of L.V. Prasad Eye Institute**, along with his wife, Mrs. Parul Garg.



Ms. Malina, an actress and model from South India, also walked the ramp. **Dr. Manisha Sahay**, a nephrologist at Osmania General Hospital, **Mrs. Gayatri Bhargavi**, a talented actress, along with her husband, **Col. Vikram Subramanyam**, walked the ramp strongly advocating the cause of eye and organ donation.



Mrs. Sameera Bharadwaj, a Telugu playback singer captivated the audience with her melodious voice. **Mr. Sailesh, Flim Director** along with his family walked the ramp.



Supporting Partners





Mrs. Meera Shenoy, Founder of Youth4Jobs, who is passionate about her work of transforming marginalized youth and youth with disabilities by training them and linking them to sustained livelihoods, walked the ramp to endorse organ donation.

Dr. Swarnalatha Guditi, a Professor and Head of the Department of Nephrology at Nizam's Institute of Medical Sciences, Hyderabad, and also in charge of the Jeevandan program in Telangana, walked the ramp.

Mr. Swastik Bihani and his wife, Raina, and daughter, Sanika walked the ramp. Mr. Swastik Bihani is currently the MD and Country Head of a US-based company in healthcare technology called GHX. His wife, Raina, has worked in various roles involving the launch of new products and markets at Google. Their 16-year-old daughter, Sanika Bihani, is a fervent advocate of organ donation. She has conducted many presentations on organ donation and educated more than 15,000 people about organ donation.

Ms. Madhavi Siddam is a renowned media personality with over 18 years of experience as a newsreader, presenter, and health correspondent. She endorsed organ donation by walking the ramp.

Ms. Vyjayanti, a courageous transwoman, who advocates for transgender rights and inclusion that has inspired many, making her a respected voice in the community, strongly advocated for organ donation.

Ms. Harshini Mekala, an artist and a Transwoman walked the ramp and spoke eloquently about organ donation.

Ms. Gundra Rosy, the Founder of the Sankalp Foundation, who has been campaigning and educating orphans and disadvantaged children since 2003 walked the ramp.

Dr. Mohammed Moiz Lalani is a pulmonary and critical care physician at KIMS Hospital Institute of Heart and Lung Transplantation along with his colleagues walked the ramp.

Ms. Shaista, a kidney transplant recipient from Gandhi Hospital proudly showed off her placard that says, "I received a kidney, thanks to an angel".

Mr. Mohan Nishtala, walked the ramp along with his daughter-in-law, Poulomi. Mr. Mohan donated his wife Lakshmi's organs in 2013 and saved seven lives.

Mr. Srinagesh, who received a heart transplant a year ago, proudly demonstrated the placard which read, "I received a Heart, thanks to an angel".



To cite : Raghuram L. Metro Retro - Ramp Walk for a Cause. Indian Transplant Newsletter. 2024 Apr-Jun; 23(2):p6-7.

Supporting Partners



Jewellery Partner Eye Donation Partner



HPB Masterclass and Cadaveric Organ Retrieval Course

Jaipur - May 2024



Naimish N. Mehta

Chairman Centre for Digestive Sciences,
Professor and Head, Department of HPB and
Liver Transplant Surgery, Mahatma Gandhi
Medical College & Hospital, Jaipur

Hepato-Pancreato-Biliary (HPB) Masterclass with training in Organ retrieval on cadaver was held on 10th and 11th May 2024 at Mahatma Gandhi Medical College, Jaipur, Rajasthan. It was a two day certificate course with primary aim of giving hands-on experience. The program included theory sessions and practical training on cadaver demonstrating retrieval of abdominal organs and vascular anastomoses. Didactic lectures included practical aspect of various surgeries in HPB including liver resection and its techniques, pancreatic surgeries, multiorgan retrieval video presentations and various case scenarios by eminent national faculty.



There were 16 participants including practicing consultants from all over India as far as North-East. Amongst the participants, two were senior surgeons from medical colleges of Rajasthan, who were very keen to initiate retrieval program at their centres which would eventually be certified as Non-Transplant Organ Retrieval Centre (NTORC) by SOTTO. Only

three participants were allotted to each cadaver to ensure that each one could gain hands-on experience with the retrieval procedure. The aim of this course was to offer this exercise to a small group to enable it to be more practical teaching and training. The certificates were distributed by Dr. M. L. Swarankar, who serves as the Emeritus Chairperson of the Mahatma Gandhi University of Medical Sciences and Technology (MGUMST).



To cite : Mehta NN. HPB Masterclass and Cadaveric Organ Retrieval Course. Indian Transplant Newsletter. 2024 Apr-Jun; 23(2):p8.

Hands-on Cadaver Retrieval and Surgical Training Workshop

Mumbai - June 2024



Dr. Sujata Patwardhan

Director - Incharge
ROTTA-SOTTO, West and Maharashtra

Regional cum State Organ and Tissue Transplant organization ROTTO-SOTTO, West and Maharashtra was established at reputed Seth G.S. Medical College and KEM Hospital, Mumbai in 2017. Under National Organ Transplant Programme [NOTP], the first cadaver tissue retrieval OT and Training center for organ and tissue retrieval was established for the Western Region in April, 2022 at K.E.M Hospital with the following objectives.

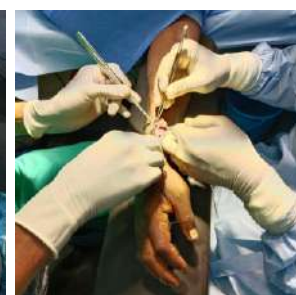
- To provide the facility of organ and musculoskeletal tissue retrieval, enabling retrieval of skin, heart valves, and other tissues.
- To conduct the training workshops for retrieval surgeons.



On June 8 - 9, 2024, ROTTO - SOTTO in collaboration with Renal Transplant section USI and Indian School of Urology conducted hands on cadaver workshop on renal transplant and

vascular anastomosis workshop at B.Y.L Nair Hospital Mumbai. The program included lectures by eminent faculties and sharing of educational videos. To ensure that every participant could gain practical experience with the retrieval process, no more than two individuals were assigned to each cadaver.

The organizing members were Dr. Sujata Patwardhan, Director, Incharge ROTTO SOTTO, Chair, ISU, Dr. Lalit Shah, President, USI, Dr. Uttam Mete. Hon. Secretary, USI, Dr. Umesh Oza, Chairman, Renal transplant Section, USI.



To cite : Patwardhan S. Hands-on Cadaver Retrieval and Surgical Training Workshop. Indian Transplant Newsletter. 2024 Apr-Jun; 23(2):p8.

Transplant Coordinators' Training Program (Face-to-face)

National Organ & Tissue Transplant Organization

The National Organ & Tissue Transplant Organization (NOTTO), Directorate General of Health Services, Ministry of Health and Family Welfare, Government of India conducted the 11th Batch of its 5-day Transplant Coordinators' Training Course from June 24 to June 28, 2024. The event took place at the Training Hall of the NIOB Building on the Safdarjung Hospital Campus in New Delhi. Prof. (Dr.) Atul Goel, Deputy Commandant of the Army Hospital (R&R), was the Chief Guest at the inaugural ceremony. The program was attended by 41 nursing officers from the armed forces and nine participants from various institutions. The curriculum included lectures and hands-on demonstrations by transplant professionals and esteemed academic members.



To cite : Kumar P. Transplant Coordinators' Training Program (Face-to-face) - National Organ & Tissue Transplant Organization. Indian Transplant Newsletter. 2024 Apr-Jun; 23(2):p9.

ZTCC Pune & ROTTO - SOTTO, Maharashtra

From June 24 - June 28, 2024, ZTCC Pune (Zonal Transplant Coordination Centre), in collaboration with ROTTO - SOTTO, Maharashtra and under the aegis of NOTTO, successfully conducted a 5-day training program for transplant coordinators. Forty-nine candidates from various parts of Maharashtra attended the training conducted at KEM Hospital, Pune. Experts delivered a series of lectures covering medical, legal, counselling and coordination of deceased donations and living donor transplants. The training also included group activities to provide practical exposure. The program concluded with the awarding of course completion certificates to the participants.



To cite : Jairam J. Transplant Coordinators' Training Program (Face-to-face) - ZTCC Pune & ROTTO, SOTTO, Maharashtra. Indian Transplant Newsletter. 2024 Apr-Jun; 23(2):p9.

Online Training for Transplant Coordinators

From April to June 2024, 104 candidates, including seven from Myanmar, successfully completed the six-week "Transplant Coordination Professional Certificate" course conducted by MOHAN Foundation. The curriculum covered a wide range of topics, including medical, legal, coordination, and counselling aspects, delivered through online modules and expert faculty lectures. Candidates participated in periodic self-assessments and assignments via the platform. Weekly webinars fostered interactive discussions with faculty, which was a key component of the course.

Mrs. Veena, Gujarat

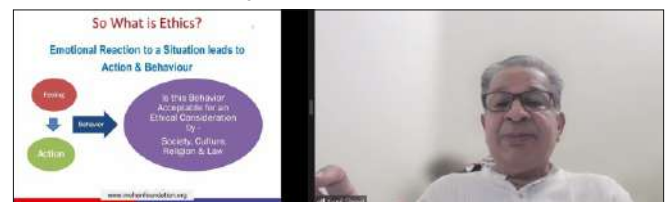
"The course proved to be helpful in getting both theoretical and practical knowledge about organ donation, organ transplants and the role of coordinators. The distribution of topics and content were well planned. I am from a non-medical field, but the sessions by transplant doctors are at par excellence. Thanks to MOHAN Foundation and the team to this wonderful course and hope it will be a stepping stone in my career as transplant coordinator."

April - May 2024 Batch



Ms. Mayuri Barge discussing the procedures involved in deceased organ donation

May - June 2024 Batch

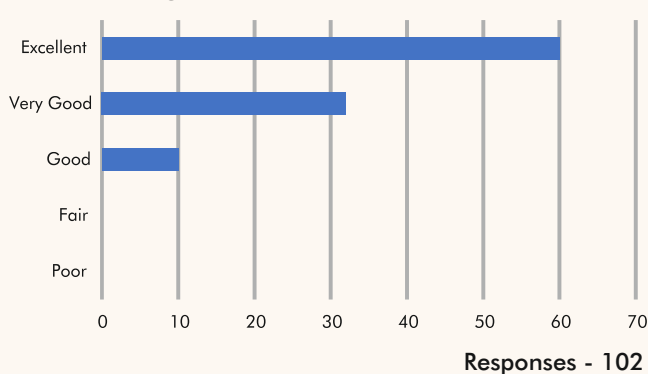


Ethical aspects of organ donation by Dr. Sunil Shroff



Roles and responsibilities of a transplant coordinator by Ms. Trilly Racheal Mathew

Overall ratings for the course



To cite : Shroff S, Suriyamoorthi S. Online Training for Transplant Coordinators. Indian Transplant Newsletter. 2024 Apr-Jun; 23(2):p9.

Ethical Living Donation Depends on Independent Advocacy



Prof. Brendan Parent, JD
 Director of transplant ethics and policy research and assistant professor at NYU Grossman School of Medicine

Living organ donation is a unique area of medicine. It is one of the only clinical practices that will impose physical risks on a patient - the donor - without providing any potential medical benefits to this patient. Such a practice is justified by four facts: (1) The risks to the donor must be sufficiently low; (2) The likely benefits to the potential transplant recipient must be sufficiently high; (3) the donor must give full informed consent; and (4) the risk/benefit calculus for the potential donor must be expanded to include spiritual, emotional, and relational benefits and risks. The dire

need for more transplantable organs, and the pressures on hospitals to obtain organs for transplant, mean that no clinical team performing living donations should have sole responsibility for meeting these requirements. Living donors need and deserve independent living donor advocacy. This protects not just donors, but living donor programs, and the field of transplant medicine.

All patients deserve advocacy. But the people who usually serve as patient advocates for other medical concerns – loved ones and clinicians – sometimes have insurmountable conflicts of interest in the living organ donation context. The potential transplant recipient, or someone who cares about both the donor and the potential recipient, cannot be expected to objectively advocate for the donor's best interest. It would also be unreasonable to expect clinicians and clinical programs that have stakes in living donor transplant outcomes to objectively assess whether donation is in an individual's best interest. Doing so requires independence from both the recipient and from the hospital, such that one's allegiance is only to the donor.

To be effective, Independent Living Donor Advocates (ILDAs), cannot operate alone. While ILDA's must be knowledgeable about living donation and able to convey general statistics, the medical team understands the clinical risks specific to the donor and potential clinical benefits for the recipient. To meet the ethics requirements of ensuring an appropriate clinical risk/benefit profile, these must be conveyed to donors in ways they can understand, and the clinical team is best suited for this job. But for potential donors to provide informed consent - meaning they comprehend clinical risks in context of their own values and goals, including navigating feelings of duty to family while prioritizing their own interests - requires an ILDA who only cares about the donor.

Even members of the living donor team trained in psychology and social work cannot overcome assessment barriers built into hierarchical doctor-patient relationships. Some potential donors do not want to let clinicians down, or do not trust that what they tell the

donor team will not somehow get back to the recipient. When the ILDA enters the evaluation and tells the patient, "I'm here to support you, to help you think through what it means to donate, I only care about you, I don't work for these guys," the patient often opens up in ways they did not previously.

This allows the ILDA to ensure that the final ethics requirement of living donation is met – that the potential donor can weigh risks and benefits beyond the physical. Donors often experience extraordinary psychosocial benefits, knowing they helped save someone's life. Many societies, cultures, and religions see no morally greater act. When individuals find such meaning, it can enhance their own quality of life. But this benefit cannot be assumed. No matter how clinically safe, living donation involves invasive surgery with recovery time, which can mean changing or canceling significant life plans, losing income, complications for bodily identity, unreasonable expectations for relationships between donor and recipient post-donation, and feelings of failure or guilt if the transplant is not successful. No person should be expected to participate in living donation against their will, under undue influence, or without adequate information or capacity.

Parsing out the potential psychosocial, emotional, and relational implications of living donation is challenging. It is hard to find someone not employed by the transplant program with the requisite time and expertise. And most cases are not clear-cut examples of coercion, like donors being promised large sums of money or facing threats of physical force. Often, potential donors are conflicted, wanting their loved ones to survive and live better, but are simultaneously scared and feeling guilty about not wanting to reroute their lives. It is often unclear even to well-trained ILDA's how to strike the balance between enabling the patient's autonomy, while protecting the patient. But having an ILDA as a required part of the evaluation lends integrity and credibility to the process. The lives of potential donors are always as important as the lives of potential recipients. Giving potential donors someone "in their corner" can preserve trust in transplant, which ensures donors keep coming forward.

About the author

Brendan Parent, JD is Principal Investigator on government and foundation grants studying ethics and regulation of transplant research. Parent serves as an independent living donor advocate, an advisory board member for the National Kidney Foundation, and a member of the national donation leadership council for The Alliance. He provides ethics consultation for transplant and medical research programs across the United States. Parent's current work also focuses on ethics challenges surrounding determination of death by neurologic criteria, research on the deceased, and big data and artificial intelligence in health research. He has published academic articles in peer reviewed journals spanning law, medicine, science, sports, and ethics, and his work has been featured in the Washington Post, The NY Times, Wired, Chicago Tribune, The Guardian, and on NPR. Previously, he was a legal fellow for the New York Task Force on Life and the Law, the first Rudin Post-Doc in the NYU Division of Medical Ethics, and received his JD from Georgetown University Law Center.

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Impact of Sustainable Development Goals on Organ Donation and Transplantation

The Sustainable Development Goals (SDGs) have profoundly influenced organ donation and transplantation through a global framework, particularly SDG 3: Good Health and Well-being. This goal emphasizes ensuring healthy lives and promoting well-being for all ages. It prioritizes maintaining a positive health status, reducing mortality rates, and enhancing health outcomes. By ensuring access to affordable surgical procedures, SDG 3 has contributed to universal health coverage, narrowing the gap between privileged and underprivileged populations. Increased investments in health systems worldwide have been crucial in providing risk protection and building resilience against health threats.⁽¹⁾

SDG 4: Quality Education also plays a significant role in the realm of organ donation. By promoting inclusive and equitable quality education and lifelong learning opportunities, public awareness campaigns and knowledge dissemination about organ donation have helped overcome cultural and religious barriers. It emphasizes the importance of building a skilled workforce for organ procurement, transplantation surgery, and post-transplant care to provide standardized and high-quality services.⁽²⁾

SDG 8: Decent Work and Economic Growth is another critical factor, promoting consistent, inclusive, and sustainable economic growth. In 2023, global economic growth increased by 2.3%, which, coupled with sustainable resource management, has made healthcare systems more effective. Cost-effective solutions, such as organ transplant, offer a viable alternative to expensive chronic treatments like dialysis, which consumes significant resources.

SDG 10: Reduced Inequalities addresses the challenge of socioeconomic disparities, ensuring equitable access and fair allocation of resources. The Transplantation of Human Organ Act (THOA) and SDG 10 work towards compliance regardless of age,

gender, ethnicity, religious beliefs, and economic status. By implementing strict measures, these frameworks aim to prevent trafficking in human organs, and ensure the safety of vulnerable individuals.

SDG 16: Peace, Justice, and Strong Institutions promotes inclusive societies, access to justice, and effective institutions. It addresses ethical concerns in organ donation, emphasizing the conscience of invasion, consent without coercion and clinical evidence of death.⁽³⁾

SDG 17: Partnerships for the Goals emphasizes the importance of global collaboration in organ donation systems. Sharing data, skills, and resources has increased capacity and availability. Public education campaigns help dispel misconceptions and promote consent within families. Multi-stakeholder partnerships, including public, public-private, and civil society-based collaborations, enhance donation and funding opportunities, contributing to a more extensive outreach for sustainable development in organ transplantation.

"If we are prepared to receive a transplant should we need one, then we should be ready to give" - The World Health Organisation on Transplantation of human cells, tissues and organs.

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Anudaan : Making Transplants Affordable - An Initiative Touching Lives...

"Anudaan - Making Transplants Affordable" is a MOHAN Foundation initiative launched in 2021 to provide financial aid for life-saving transplants to economically underprivileged individuals.

Transplants Supported:

Apr to Jun'24:

6 Transplants
4 Kidney, 1 Liver, 1 Cornea;
2 Pediatrics, 4 Adults

Inception to Jun'24:

71 Transplants
43 Liver, 18 Kidney, 2 Heart, 8 Cornea;
39 Pediatric, 32 Adults

Anudaan Supporters

- Special thanks to **Mr. Ranjan Pal, Mr. Sunil Chainani and Mr. Sanchit Arora** for their generous donation.
- Mr. Kalpesh Singh Rathod:** Special thanks for consistent support through monthly donations.

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A MOHAN project

अनुदाAN
Making Transplants Affordable

An initiative touching lives...

- ASPIRES TO BE A COMPUTER ENGINEER**
MAHADEV RAJENDRA GAIKWAD
18 yrs, Pune, Maharashtra
Kidney Transplant on February 9, 2024
- MS. PREMA**
28 yrs, Noida, Uttar Pradesh
Corneal Transplant on May 5, 2024
- ASPIRES TO BE A ENTREPRENEUR**
MR. PUSHPRA J SIDDHARTH GAIKWAD
36 yrs, Pune, Maharashtra
Kidney Transplant on May 16, 2024
- ASPIRES TO BE A DOCTOR**
MS. HANSEI SANJAY SONAR
21 yrs, Nashik, Maharashtra
Kidney Transplant on May 14, 2024
- ASPIRES TO BE A ARMY OFFICER**
MASTER KARTHIK M
16 yrs, Kalaburagi, Karnataka
Liver Transplant on May 7, 2024
- ASPIRES TO BE A MOTORCYCLE MECHANIC**
MAHMAD AYUB JINER
37 yrs, Osmanabad, Maharashtra
Kidney Transplant on April 23, 2024

Support this endeavour and enable us to aid many more transplants and aspirations





MOHAN
FOUNDATION

Project
GIFT HOPE, GIFT LIFE
(May 2021 - March 2024)

Supported by
SBI FOUNDATION
Service Beyond Banking



Mr. Sanjay Prakash
MD, SBI Foundation

State Bank of India (SBI) is seen as the ubiquitous 'household bank' all over India. Any philanthropic initiative supported by SBI creates a ripple effect by addressing the social issue and at the same time creates awareness in millions of Indians and encourages other corporates to come forward as well.

SBI through its CSR arm, SBI Foundation has been supporting the cause of Organ Donation since the year 2016 and it has emerged as one of biggest Champions of promoting Deceased Organ Donation in India.

Through its long-term association with MOHAN Foundation through the "Gift Hope, Gift Life" project, SBI Foundation has made a profound impact on organ donation ecosystem in India through policy advocacy initiatives, promoting awareness, education and capacity building on Organ Donation.

I am proud to share that our support in the last 3 years from April 2021 has successfully sensitized more than three lakh individuals, significantly enhanced public understanding of the critical importance of organ donation. Additionally, 30,138 callers contacted the SBI-MOHAN Foundation helpline to learn about transplant options, understand the process, and how to take the pledge. We have also supported training of 2,328 healthcare professionals, including ICU doctors, nurses, transplant coordinators, and transplant surgeons, to ensure that they are equipped with the knowledge and skills necessary to facilitate organ donation effectively.

Support group meetings and educational sessions under the project have benefited 23,814 patients suffering from end-stage of organ failure. Most notably, 3,280 patients have received life-saving organs and tissues, including corneas, skin, and bones, which has significantly enhanced their quality of life.

This remarkable achievement reaffirms our commitment to advancing public health and underscores the essential role we play in promoting a culture of compassion and responsibility.

The association of SBI Foundation with this transformative project is a testament to our dedication to supporting vital healthcare initiatives and making a meaningful difference in the lives of individuals and families in need.

"Together, we are not just advocating for organ donation; we are changing lives."