Progress with Deceased Donation in India

Deceased organ donation in India reached its peak in 2016, followed by a plateau for four years, and a decline during the COVID-19 pandemic. However, last year marked a significant improvement. The 2022 data showed an increase in both living and deceased donations. Moreover, the year recorded the highest number of living kidney and liver transplants ever, with 9,834 and 2,957 cases, respectively. In 2022, the total number of liver transplants from deceased and living donors also reached an all-time high of 3,718.

Despite the progress, India is yet to achieve an organ donation rate of 1 per million population. Some Indian states have outperformed, with a few achieving donation rates as high as 34 per million population (UT-Chandigarh). However, in these states too, most donations come from just one or two cities and a few hospitals. The issue of regional disparity in donations is not unique to India and can be attributed to factors such as education and lack of access to healthcare.

Tertiary care corporate hospitals account for the bulk of donations, while public sector hospitals contribute less than 15%. Heart utilization for transplants from public care hospitals is under 10%, due to poor maintenance, compared to 70% from private hospitals. But, the true potential for deceased donation in India lies in public sector hospitals, where a large number of head trauma cases are admitted due to their medico-legal implications. If each state had one nodal hospital focused on deceased donation, it could improve the organ donation rate and provide more affordable transplant options to patients from the less affordable class. NOTTO, our national organization, is now better equipped, and it is hoped that they will work towards empowering public care facilities.

This issue is dedicated to lung transplants, and there are some interesting statistics and articles.
In the news - International

First-ever Deceased Organ Donation In Bangladesh

Bangladesh witnessed its first-ever deceased organ donation in January 2023 with the retrieval of two kidneys and corneas from a brain dead donor. The donation was made possible by the Human Organ Transplantation (Amendment) Act of 2018, which authorized the retrieval of organs from brain dead donors. The organs were retrieved from Sarah Islam, a 20-year-old first-year Fine Arts student. Sarah had been suffering from a rare genetic disease since she was 10 months old. Her health gradually deteriorated, and she underwent a surgery at the Bangabandhu Sheikh Mujib Medical University (BSMMU), where her condition worsened and she was subsequently declared brain dead by the attending physicians.

Her mother Shabnam Sultana, a schoolteacher was approached by the doctors and subsequently gave permission for donating Sarah's kidneys and corneas. The kidney transplant was received by two female patients, one from the BSMMU and the other from the National Kidney Foundation Hospital. Sarah's donation also enabled corneal transplants performed on two patients.

Utah Woman Donates Two Organs While Alive, Saves Two Lives

Robin Vedaa, a resident of Midvale, Utah, has accomplished an extraordinary act of generosity by donating two of her organs while still alive. This selfless act has made her one of the very few individuals in the world who have done so, with nearly 100 people globally making this remarkable contribution to others. Her donation of a kidney in 2019 and 20% of her liver in January, 2023, have saved the lives of a young woman and a child.

DonorConnect, a local organization that connects donors with recipients, reported that 883 people in Utah were on the waiting list for vital organs. Robin Vedaa's act of kindness has given hope to those on the waiting list and demonstrated the power of organ donation in saving lives.

Vedaa stated that she felt compelled to give the gift of life to strangers in need. "Hearing about the statistics and the numbers, I thought, "Wow, there are still so many people waiting for organs, I gave my kidney to an adult, so why not this time … give to a child," said Vedaa. She added that that the surgery had given her a new perspective on life and encouraged others to consider donating.

World's First Centenarian Donation After Death Performed In Italy

In November 2022, Italy's Ministry of Health reported that a 100-year-old woman's liver was successfully transplanted to another patient, marking the first time such a procedure was carried out from an elderly donor. The donor was 100 years, 10 months, and one day old. This was the first ultra-centenarian in the world to donate her organs after death. Recent evidences indicate that organs from older donors are no longer rejected solely because of their age, especially in liver transplant programs.

The donation was carried out at San Giovanni di Dio Hospital in Florence. Her liver was donated to a patient on the waiting list at the University of Pisa Hospital. Five other cases of 97-year-olds have previously been recorded as the oldest organ donors, including the previous record of 97 years and 7 months carried out in Italy in 2021.

Virtual Cross Match Using AI To Predict Compatibility

Virtual cross-matching is a technique used to predict the compatibility of a donor and recipient in organ transplantation. This method relies on analyzing genetic data and has been made more efficient through the use of artificial intelligence (AI) algorithms. AI-based virtual cross-matching has the potential to revolutionize organ transplantation by reducing the time and cost associated with traditional cross-matching methods.

In a recent study published in the Journal of Transplantation, researchers used a machine learning-based approach to develop a virtual cross-matching algorithm for kidney transplantation. The algorithm used genetic data from the donor and recipient to predict the likelihood of a successful transplant. The researchers found that the algorithm was able to accurately predict transplant outcomes and could potentially reduce the need for expensive and time-consuming cross-matching tests.

FORM – IV

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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
In the news - National

Gujarat High Court Rejects State Domicile Priority For Deceased Donor Transplants

The Gujarat high court overturned the state's policy that gave preference to Gujarat residents for transplanting organs from deceased donors.

The high court of Gujarat received three such petitions - Hemali Ajmera (who needed a kidney transplant), a Canadian citizen who has been living in India (Ahmedabad) for 13 years; Vidhya Shah (who needed a liver transplant), a Gujarati descent but a resident of Madhya Pradesh; Himanshu Shekhar (who needed a kidney transplant) from Jharkhand who had been living in Ahmedabad for seven years. All three of them were not registered on the state waitlist as they were denied the state domicile certificates.

A person without Gujarat domicile status does not get priority on the list of recipients and cannot register on the state list under the Gujarat Deceased Donor Organ and Tissue Transplantation Guidelines (G-DOT). According to the state government, its policy of favouring locals for cadaver transplants was due to the shortage of organs and aimed at preventing organ transplant tourism.

However, the court rejected the statements made by the state. In its order issued in November 2022, the court directed the state that the right to life is above the domicile certificate. It added in its judgement that neither the right to health nor the right to life shall be restricted by the state, only to its domiciles.

India's First Paediatric Liver Recipient Is Now A Medicine Graduate

Sanjay Shakkthy Kandaswamy, a one-and-a-half-year-old child from Kanchipuram (Tamil Nadu), became India's first successful paediatric liver transplant recipient in 1998. For Sanjay Kandasamy, life has come full circle as he is now a qualified doctor, 24 years after his transplant.

Sanjay was born with biliary atresia, a congenital disorder that led to liver failure, and eventually needed a transplant. His father was the donor and the transplant was performed at the Indraprastha Apollo Hospitals, New Delhi by a team of experts consisting of Dr M R Rajashekar, Dr A S Soin and Dr Anupam Sibal.

“He is a classic example of long-term survival after undergoing a liver transplant surgery,” said Dr Anupam Sibal, the group medical director and senior paediatric gastroenterologist at Indraprastha Apollo Hospitals.

“It is one of the proudest moments in my 28-year career as a transplant surgeon. My baby patient is all set to become a doctor,” said Dr A S Soin, who is currently the chairman of institute of liver transplantation at Medanta Hospital.

With great gratitude to his doctors, Dr Sanjay says, “Seeing their work from such close quarters gave me the determination to become a doctor. I want to contribute to saving lives, and set an example that one can overcome any challenge in life.”

17-Year Teen From Kerala Is Successful In Her Plea To Donate Liver To Her Father

The Kerala High Court granted permission to a teenage girl to donate a portion of her liver to her sick father. Devananda, a 17-year-old girl from the Thrissur district of Kerala, filed a writ petition asking to be exempted from the age requirement for living donors as set in the Transplantation of Human Organs and Tissues Rules, 2014.

Her father, Pratheesh P. G. needed a liver transplant due to his decompensated chronic liver disease and hepatocellular carcinoma. Considering the long waiting list for deceased donor liver, Pratheesh's family opted for a living donor transplant. The only liver that matched him among his close relatives was his daughter, Devananda's. But, Devananda was not allowed to donate as she was only 17 years old.

Considering an expert committee report compiled by the Kerala State Organ Tissue Transplant Organization (K-SOTTO), which had been commissioned by HC to examine Devananda’s case, the court gave the judgement in December 2022. The committee based their decision on key facts, that a transplantation was the only available option for Pratheesh and that the donor made a voluntary and informed decision to donate without any external pressure or influence. “The writ petition was disposed of permitting her to donate a portion of her liver for conducting her father's transplantation surgery, subject to the other requirements of the Act and the Rules,” the court said in the order.

In 2022, 41% of Transplanted Kidneys In Gujarat Came From Cadavers

In 2022, the State Organ and Tissue Transplant Organization (SOTTO), Gujarat, achieved a significant milestone by performing the highest number of renal transplants from deceased donors in the state. There were 388 kidney transplants performed, of which 159 were retrieved from deceased donors, representing 41% of the total transplants. This was far more than the previous years’ performance where the proportion of kidney transplants from deceased donors remained within the range of 8% to 19% from 2012 to 2015.

Dr Vivek Kute, Secretary, Indian society of Organ Transplantation (ISOT), said that as far as Gujarat was concerned, 41% of transplants from cadavers was the highest ever recorded. ‘The need of the hour is to improve awareness of kidney diseases and transplantation. The rise in cadaver donations will reduce the huge gap between demand and supply,” he added.

Dr Prakash Darji, a nephrologist and transplant physician from Ahmedabad, credited the greater availability of ventilators due to COVID-19 pandemic for the increase in cadaver donations and the eventual availability of kidneys for transplantation.

While talking about restoring transplants to their pre-pandemic level at Mulijbhai Patel Urological Hospital in Nadiad, Dr Ajay Gangoli said, “There has been a transplant volume increase, but we don't have adequate data to ascertain if kidney failure has also increased”. 

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Introduction:

Lung transplantation (LTx) is now a well-accepted treatment option for a variety of selected end-stage lung diseases (ESLD) which improves survival rates and quality of life. The International Society for Heart and Lung Transplantation Registry reports a 1 and 5-year survival of 85% and 59%, respectively, for adult lung transplant recipients transplanted since 2010.[1]

The current indications of LTx are, but not limited to, chronic obstructive pulmonary disease (COPD), interstitial lung diseases (ILDs), cystic fibrosis (CF), non-CF bronchiectasis, and pulmonary hypertension. LTx is not usually considered in patients with acute lung injury (ALI) due to any infectious cause. However, there has been a paradigm shift in the treatment strategy in the cohort of ALI due to COVID-19.[1]

Three methods of LTxs are possible. These are single lung transplant through posterolateral thoracotomy, double lung transplant with a clamshell incision, and combined heart and lung transplant as enbloc through median sternotomy.

Lung Transplant in India:

The first HLTx in India was performed by Dr K M Cherian and group in 1999[7]. On July 11, 2012, Dr. Jnanesh Thacker, performed the first successful lung transplant in India. Subsequent to this, there were few reports of heart and lung or lung transplants discretely in the first ten years. [1]

At present, there are a few lung transplant centers in India which cover a wide geographic area (Fig. 1).[1] Yet some major challenges remain, such as inappropriate timing of referrals, distance to the referring hospitals, lack of infrastructure, social taboo associated with organ donation, and lack of coordination between different centers.

Challenges in Indian settings at present:

1) At donor level: Poor organ donation rates
2) At recipient level: Delayed referrals
3) At logistics: Remote areas of retrieval, Charter flight options, etc

Organ Donation in India: As per GODT, there were 552 (0.43 pm) actual deceased donors in 2021 as compared to 715 in 2019 (0.52 pm) pre-COVID pandemic. 133 lung transplants happened in 2021 as compared to 114 in 2019, pre-COVID pandemic.[2]

The rise in Lung Transplants has been partly attributed by the COVID pandemic which led to few select patients with Post-COVID ARDS, end stage lung disease requiring lung transplant and also because awareness among medical fraternity regarding availability of lung transplant services.

Future in Lung Transplant:

In view of more number of extended criteria donors, there was a need for research regarding expanding donor pool. Hence, came two game-changing concepts which when applied were able to increase donor pool, helping in turn to reduce wait-list mortality. These are (a) Ex Vivo Lung Perfusion (EVLP) and (b) Donation after Circulatory Death (DCD).

a) EVLP: This is a technique used to evaluate and screen compromised donor lungs with potential for recovery. This technique has been already used in LTx centres across the world. EVLP can restore the circulation and ventilation of the ex vivo lung. At an ambient temperature of 37°C, a membrane oxygenator is used to simulate oxygen consumption in the body via deoxygenation and maintain the physiological state of lungs with specific perfusate and ventilation. EVLP is currently used mainly to evaluate certain high-risk donor lungs. It is mainly indicated for (I) an oxygenation index <300 mmHg; (II) pulmonary oedema as indicated by the last chest X-ray; (III) collapse or poor expansion of a donor lung during harvest; (IV) blood transfusion >10 U; and (V) lungs from donors with cardiac death. EVLP is not suitable in cases of apparent pneumonia, severe mechanical lung injury (including multiple lobar injury) or significant aspiration of gastric contents. [3]

**EVLP: will help optimise marginal lungs before implanting, thus improving outcomes and increasing donor pool.**

b) DCD: Here, organs are removed from donors after cardiac arrest. DCD can be considered in a patient who does not fulfill brainstem death criteria, but has no hope of recovery, and it is in the best interest of the patient to withdraw life-sustaining treatment. The main difference between DCD and donation after brainstem death (DBD) organs is the warm ischemia time. Warm ischemia will be minimal in DBD donors as compared to DCD donors, where there is an interval after asystole where organs are not being perfused and have not yet been cooled, leading to relatively longer warm ischemia time.

References:

6. Referrals for optimisation, to incorporate services like EVLP, ECP, etc; is a need to improve transplant outcomes.
In India, the concept of DCD is evolving, with want of more legal clarity regarding treatment withdrawal of life support. When decision to withdraw treatment support has been taken by the family and the physician, discussion regarding organ donation can be initiated.[3]

DCD: will help increase the donor pool and will lead to reducing waitlist time in future.

Other Recent Advances in Lung Transplant

c) Cell-free DNA (cfDNA) is released from cells into the surrounding tissue and bloodstream during apoptotic and necrotic cellular decay and can be detected in plasma and serum. An association exists between circulating levels of cfDNA and acute lung injury, sepsis, and malignant disease. Improved technical development has made it possible to differentiate donor-derived cfDNA (dd-cfDNA) from recipient-derived cfDNA (rd-cfDNA) in the bloodstream. Thus, quantification of each portion can be made, and the ratio of dd-cfDNA to all cfDNA, also called the donor fraction (DF), has been associated with graft injury after kidney, liver, heart and lung transplantation. [4]

%ddcfDNA significantly increased at the time of histopathological grade moderate or severe ACR (ACR grade ≥ 3) vs stable controls. A threshold dd-cfDNA level of >1% demonstrated 100% sensitivity and 73% specificity for the diagnosis of moderate or severe ACR with an area under the receiver-operating characteristic curve (AUC) of 0.9. Taking the available evidence into account, dd-cfDNA, reported as %ddcfDNA appears to demonstrate good diagnostic accuracy for the diagnosis of acute rejection in lung transplant patients. [5]

This test will in future reduce the need for frequent lung biopsies post lung transplant to monitor rejection.

d) ECP: Extracorporeal Photopheresis: Data from these studies suggest that ECP therapy is associated with improvement or stabilization in lung function and sustainable, statistically significant decreases in the rate of lung function decline in patients with Bronchiolitis Obliterans Syndrome (BOS).

Furthermore, two studies reported that 25% to 30% of patients with BOS have an improvement in lung function after treatment with ECP. Extracorporeal photopheresis was generally safe and well tolerated. [6]

ECP: might become an important modality to treat CLAD where not much successful options are available.

Conclusion: Lung transplantation is still the only option that can be offered to the majority of selected end-stage lung disease patients with presumed modest improvements in quality-adjusted survival. India will need to have multipronged approach to improve organ donation rates, to create awareness for Early Referrals for optimisation, to incorporate services like EVLP, ECP, ddcfDNA, etc which are going to be game changers in the field of lung transplantation.

References:
Karnataka's deceased organ donation program made a remarkable progress in 2022, recording 151 deceased donations and securing the state's position as the third highest in India, following Telangana and Tamil Nadu.

The Transplantation of Human Organs Act, 1994 issued by the Government of India, was adopted by the Legislative Assembly of Karnataka in 1995. The state's journey towards deceased donations began in the same year with the establishment of FORTE (Foundation for Organ Retrieval and Transplant Education), a non-governmental organization based in Bengaluru. In 2005, FORTE was merged with the state-supported ZCCK, which worked towards streamlining and coordinating deceased donation activities in Karnataka. Later, in 2017, ZCCK underwent a transformation to become an autonomous registered society named Jeevasarthakathe. Subsequently, in 2022, Jeevasarthakathe was formally recognized as SOTTO-Karnataka (State Organ and Tissue Transplant Organization) by the Central Government.

Karnataka has established five zones across the state, namely Mangaluru, Mysuru, Hubballi-Dharwad, Kalaburagi, and Bengaluru serving as the headquarters. In order to improve the program, it has undertaken a number of measures, including creating an enabling ecosystem for organ donation and transplantation, streamlining the deceased donation process, and creating strong partnerships with various stakeholders such as hospitals, medical professionals, government and non-government agencies. In addition to these measures, SOTTO Karnataka has also been actively involved in raising awareness among the general public.

Pathbreaking work by SOTTO - Karnataka

- Identifying Non-Transplant Human Organ Retrieval Centres (NTHORC) and supporting their licensing and facilitating deceased donations
- Maintaining online registries for transplant wait list and pledge registry
- Organ-based advisory committees were formed to make clinical decisions regarding the offered organs
- Expert committee for brain death certification was formed to support and handhold the ICU professionals when required
- Ongoing capacity building programs conducted for stakeholders

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The above table includes data for multi-organ transplants such as heart & lung, kidney & pancreas, liver & kidney.

Karnataka sees rise in organ transportation

In 2022, over 100 green corridors were established between various cities of the state to transport not just heart and lung but also other organs when the distance was quite far.

Green corridor tweeted by Dr Keshava Sudhakar, Honourable Minister for Health and Family Welfare, Government of Karnataka
It was reassuring to read that organ donations and transplants are slowly inching towards the pre-pandemic levels in Tamil Nadu. Tamil Nadu has always been in the forefront of healthcare. I recollect with nostalgia, the public reaction to an article published in The Hindu on Jan 21st 1996 [ref: Indian Transplant Newsletter Vol. II Issue No: 6 (June 2000)] where I had shared my emotional turmoil in facilitating South Asia’s first multi-organ transplant after brain death certification. Several months earlier I had presented a paper at the annual conference of the Neurological Society of India at Kochi in December 1994 on viewing the critically ill head injured patient as an organ donor. The presentation and subsequent publication created a furor. Most neurosurgeons at that time opined that we should not take proactive measures in encouraging organ donation for fear of being branded as ‘Organ procurers’. However, the response from the general public even then was encouraging. Serendipity or otherwise, I had retained a few of the dozens of letters which the editor of The Hindu had forwarded to me. It is difficult in 2022 to understand a world without email, a world where one had to write on a post card or inland letter or go to the post office and buy a stamp to applaud and send encomiums to the team which did India’s first multi-organ donation. These sample letters which have been preserved, speak for themselves. From 1996 to possibly 2002 or so, I would have certified at least a hundred brain deaths. These sample letters which have been preserved, speak for themselves.

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K. Ganapathy
Distinguished Professor Tamilnadu Dr MGR Medical University
Emeritus Professor National Academy of Medical Sciences
Former Secretary & Past President Neurological Society of India
Past President, Telemedicine Society of India
Director, Apollo Telemedicine Networking Foundation
Apollo Telehealth Services

India’s First Multi-Organ Donation

Down Memory Lane

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A workshop on ‘Improving Living Donation’ was conducted by MOHAN Foundation on February 12, 2023, at Abu Sarovar Portico Hotel in Chennai. This Advanced Transplant Coordinators’ workshop was supported by the SBI Foundation and SBI Card. A total of 33 delegates from India and abroad attended the workshop. The meeting had discussions on the following topics:

- Use of social media to improve donations
- Special judgements on living donations
- Non-directed altruistic donation

Faculty for the workshop included experts from Kerala, Maharashtra, Tamil Nadu, Telangana and Gujarat and some were connected via virtual platform. The learnings from the workshop included the following:

- Social media shall be used positively to improve living donations. While other countries have witnessed success stories and have had long domino transplant chains, the transplant law in India is silent about the use of social media to solicit organs for transplant. The transplant societies in India shall outline guidelines for facilitating living organ donations using social media.

- Most of the judgements with regard to living donations, support organ failure patients and the judgements are given in favour of the donation and transplant. (Ministry of health and family welfare, Govt. of India issued an order to remove the condition for requirements of domicile certificate for registration of patients requiring deceased donor organ for their transplant)

- There have been many recent cases of individuals coming forward to donate their organs altruistically while they are alive. To make non-directed donations possible, India needs an exclusive altruistic donor registry as well as allocation guidelines for distributing such organs.

Panel Discussion on Non-Directed Altruistic Donation

Dr. Vijaya Sethumadhavan (Senior Nephrologist, The Voluntary Health Services Hospital, Chennai), Dr. Rajasekara Chakravarthi (HOD - Nephrology & Transplant Services, Yashoda Hospitals, Hyderabad), Ms Pallavi Kumar (Executive Director, Delhi-NCR, MOHAN Foundation), Dr J Amalorpanvanathan (Senior Consultant, Dept. of Vascular Surgery & Head - Transplant, MGM Healthcare, Chennai)

Role of social media in increasing living donation

Dr Sanjeev Nair
Nephrologist, Saveetha Medical College Hospital, Chennai

Dr Arvind Conjeevaram
Nephrologist & Transplant Physician, Trustwell Hospital, Bengaluru

Special Judgements on Living Organ Donations - Panel Discussion

Dr Mathew Jacob (Senior Consultant, Liver Transplantation & Hepatobiliary Surgery, Aster Medcity Hospital, Emakulam), Dr Sunil Shroff (Managing Trustee, MOHAN Foundation), Dr Noble Gracious (Executive Director Kerala - SOTTO), Dr Rajasekara Chakravarthi (HOD - Nephrology & Transplant Services, Yashoda Hospitals, Hyderabad), Mr Prashant Ajmera (Founder, Ajmera Law Group), Mr Anil Srivatsa (Managing Trustee, Gift of Life Adventure Foundation Inc.)

Ms Lisa Burnapp (Consultant Nurse, Associate Medical Director, Living Donation and Transplantation, NHS Blood and Transplant) speaking on Non-directed altruistic donation - UK’s Experience
An advocacy workshop for living organ donors was conducted by MOHAN Foundation on February 12, 2023, at Abu Sarovar Portico in Chennai. The workshop was part of TRIOMPH (Transplant Recipients of India & Organ failure patients - a Movement to Provide Hope), an initiative of MOHAN Foundation. The workshop was attended by transplant physicians, surgeons, transplant coordinators, living organ donors and caregivers of transplant recipients. The workshop focussed on making living donation free of coercion and health insurance for living organ donors and transplant recipients.

Ms Jaya Jairam, Project Director, MOHAN Foundation presented an introduction to living donor transplant program in India and health insurance schemes not available for living donors. The discussion stressed the need for a multi-centre study on living organ donors. These studies would aid in the understanding of the facts and the necessity of health insurance for both living organ donors and transplant recipients by the health insurance firms.

A summary of the legal requirements and ethical concerns related to living organ donations was presented by Dr Sunil Shroff, Managing Trustee, MOHAN Foundation. According to the Global Observatory on Donation and Transplantation (https://www.transplant-observatory.org/), the living donor transplant accounted for 91% of the kidney transplants performed in India in 2021 (8,275 out of 9,105 transplants). The growing numbers indicate the need for establishing independent living donor advocates (ILDA) in India to promote safe evaluation and care for living donors. The panel discussed on outlining the roles of ILDA and guidelines for implementation, standard training for ILDA, scope and limitations in the Indian context.
“Anudaan – Making Transplants Affordable” is an initiative launched by MOHAN Foundation in 2021 as a mark of its journey towards saving lives for the last 25 years. This initiative aims to provide financial assistance to the economically underprivileged, thus enabling access to life-saving transplants. Most transplants take place in private sector hospitals and the prohibitive costs make them inaccessible to the poor. Since hardly any government hospitals perform transplants, affordable transplants remain elusive to the poor. Anudaan has been providing partial contribution to the transplant cost of individuals and has been working with hospitals to bring down the transplant costs.

It is being supported by philanthropic individuals and corporate houses such as Century Plyboards India Limited, Edelweiss Tokio Life Insurance, Ethos Watch Boutiques and BNP Paribas. MOHAN Foundation also partners with like-minded individuals and organisations such as THPF (Transplants Help the Poor Foundation), TANKER Foundation and MFJCF to name a few to share the transplant costs. We have also been raising funds on Milaap, our Crowdfunding partner. This quarter, six transplant individuals were supported, of which many were children under the age of 10 years. Anudaan aims to touch the lives of these individuals and help them achieve their aspirations.

Acknowledging the below for joining hands with MOHAN Foundation’s ‘Anudaan - Making Transplants Affordable’ for extending part support to patients battling organ failure and unable to afford transplants.

- Ms. Jayalakshmi Jairam
- M/s. Choudhary International Pvt. Ltd
- Mr. Sundeep Kumar
- Ms. Runa Pradeep Baksi
- Mr. Amit Bhatiani
- M/s. Dodla Parthasarathy Reddy and Lalithamma Trust
Recipient Story

The Second Innning

Rajesh Khanna, Gurugram-based organ recipient, who holds a senior leadership position in an international travel firm

I am sitting in Magnolia Bakery, my favourite café in the tony Jubilee Hills of Hyderabad. I am sipping coffee (nearly after one year) and digging into a slice of rich Belgium chocolate cake with due permission from my dietician. This moment of bliss is one of my happiest indulgences and I do not take it for granted. I have learnt to be mindful and thankful.

When I introspect and look back, it’s hard to forget the odds of battling a progressive ailment; tied to an oxygen concentrator like a helpless prisoner. In a flash of a second, it all seemed like a bad dream. Thank God, for that’s in the past now.

Late last June, I had to be dashed off in a trauma ambulance to Hyderabad from my home in Gurugram. I could not even take a flight for fear that the altitude would choke me. A prolonged Interstitial Lung Disease (ILD) complicated by a severe post-COVID complication got me to the end-stage of the ailment. I had COVID in 2020 and my dependence on oxygen shot up from a few hours in a day to 24X7. Nearly all the doctors I had consulted in Delhi and Gurugram had hinted that lung transplant would be the way forward, given the progressive nature of the ailment. I wasn’t even keen on considering a transplant, believing somehow and secretly, that I would be better if not cured.

There was also an element of fear and I had psyched myself up completely after reading about it on the Internet. Its intensely invasive nature as I understood it, was dreadful and I wanted to avoid it. I wanted to let the disease take its own course, which in other words meant, dying a little each day.

One day I took stock of my life. I looked at my young son, my wife and my septuagenarian parents and I found my answers. I told myself that I have to be around for them. They need me. I would fight for them, I vowed.

I gathered myself mentally; picked myself up and made the best decision of my life and decided to go for a double lung transplant and surrendered all my fears and fate to the Almighty.

In Gurugram, I live in close proximity with some of the best super speciality hospitals. But none had the facility of lung transplant. I had no option but to relocate as it was a long-drawn treatment process.

Our choice of Hyderabad was an outcome of a collective diligent research. We rested our case and trust at the Krishna Institute of Medical Science (KIMS). The train ride to Hyderabad in that makeshift ambulance was long and I was anxious. Finally, in the new surroundings and set-up where my parents and wife hid their silent tears; put on their bravest fronts to make it as seamlessly normal, comfortable, warm and cozy as home, I waited patiently for my turn to come.

I was called one early morning in August 2022 saying an organ donor was found. The siren-blazing ambulance took us through a busy traffic, oxygen pipe in my nose and fear in my heart. My wife’s prayer, holding my hand all through the way, comforted me all over again. I was calm. All that I recalled was being wheeled inside the operation theatre and waking up in an unfamiliar ICU room. Multiple pipes inserted into my neck, nose and body and deafening beeps of machines, I felt unreal. I made it!

I had never lost hope as there were people who took it upon themselves to cheer me. Like Dr Sandeep Attawar, Chair & Director of Thoracic Organ Transplants at KIMS. His cheerful face and encouraging words always lifted my spirits. And Dr Vijil Rahulan, Chief Transplant Pulmonologist at KIMS, whose preciseness combined with compassion, was always so reassuring.

I was finally discharged after weeks and gained new strength each day with physio and of course regimented diet. One day, I began to breathe on my own without any support. Tears welled up my eyes. My family rushed to see the miracle. We huddled and cried together. Just one more time!

Normalcy kicked in slow and steadily. One of my first public outings was to take part in the “Ramp Walk for a Cause” organised by MOHAN Foundation where I walked the ramp in support of organ donation.

Occasionally, I sit back and reflect upon my life. Often, my thoughts race to that unknown and faceless donor and the family because of whom I have a second life. Would they ever know the joy they brought to me and my family? Would they ever know that it meant the world to me? I gaze upon the stars on so many dark and gloomy nights and thank God for my life. May the donor’s family be blessed in all forms possible on earth.

I sip my coffee once again lounging in my favourite café, I truly thank my stars!
MOHAN Foundation’s one-year online ‘Post Graduate Diploma in Transplant Coordination and Grief Counselling’ enrolled 39 participants from diverse professions from India and Sri Lanka in 2022.

The course curriculum included concepts of organ donation, national transplant specific guidelines during the COVID-19 outbreak, legal and ethical aspects, medical aspects, grief counselling and transplant coordination. The study materials were made available on MOHAN Foundation’s e-learning platform and the candidates were given access for the same.

As part of the course, virtual contact sessions were conducted on various topics including counselling, soft skills and leadership. The contact sessions also included discussions such as leveraging the power of social media and fund raising for transplant recipients. Experts across the country who were on the MOHAN Foundation’s faculty board were invited as speakers. The participants were also given an opportunity to interact with experienced transplant coordinators across the country. The course included online assignments and examination.

Feedback

Dr Manjushree Bhandari
SL Raheja Hospital, Mumbai

I am very grateful to MOHAN Foundation for allowing me to enroll in the course even though I was late in applying for it. I have gained so much from attending the lectures and associated activities. Overall course content was comprehensive and engaging.

The one-month online ‘Transplant Coordinators’ Professional Certificate course was effectively conducted by MOHAN Foundation. A total of four batches were trained between November 2022 and February 2023. The course design included online modules and interactive contact sessions through webinars which aimed to provide an engaging and informative learning experience.

140 candidates trained

56
34
28
22

NOV 2022  DEC 2022  JAN 2023  FEB 2023

Lt. Col. Sreelatha T (February - 2023)

Very informative and educative sessions and interactive webinars conducted during the course. Quiz after each module helped a lot.
Internation Conference

Initiatives On Organ And Tissue Donation And Transplantation In Abu Dhabi

The Department of Health, Government of Abu Dhabi organized an international conference for ‘Initiatives on Organ and Tissue Donation and Transplantation’ on November 7 - 9, 2022 at the Abu Dhabi National Exhibition Centre.

At the inaugural ceremony, H.E. Abdulla Al Hamed, Chairman, Department of Health - Abu Dhabi (DoH) launched ‘Hayat’ (meaning Life), the National Programme for Organ Donation and Transplantation and became the first to register as an organ donor. In recognition of their selfless giving and contribution, donors’ families and organ recipients were honoured during the conference. MOHAN Foundation was one among many organizations which was recognised for its contribution over the past 25 years. Mrs Lalitha Raghuram, Country Director accepted the award on behalf of the organization.

In light of the global organ shortage, Dr Ali Al Obaidli, Chairman, National Transplant Committee, UAE said that the initiative emphasized the importance of raising community awareness. More than 200 faculty and delegates from Middle East and North Africa attended the conference.

It was a hybrid conference with sessions highlighting the work done in the Middle East and neighbouring countries. There were scientific sessions on brain death determination and organ and tissue transplants including lung, liver, paired kidney transplant and cornea.

During the conference, emphasis was placed on education and capacity building, promotion, cross border transfers and establishment of national systems. Over 20 inspiring stories of organ recipients, donors, and their families in honour of their contributions to saving lives were highlighted during the conference.

Expert talks given by the MOHAN Foundation were ‘Role of non-governmental organizations in capacity building - Experience from India’ by Dr Sunil Shroff, Managing Trustee and ‘Professional education opportunities in India’ by Mrs Lalitha Raghuram. An information desk was set by the MOHAN Foundation to talk about professional training opportunities and awareness initiatives in India.

MOHAN Foundation At The Second International Transplant Conference, Nepal

The 2nd International Transplant Conference on ‘Deceased Donor Transplantation for Developing World’ was held on November 12-13, 2022 at Kathmandu, Nepal. The conference was jointly organized by NESOT (Nepalese Society of Organ Transplantation) and Shahid Dharmabhakta National Transplant Centre.

Ms Pallavi Kumar, Executive Director - NCR, MOHAN Foundation was invited as an international speaker. She addressed the audience on ‘Starting deceased donation program in a hospital’ and ‘Breaking bad news and making the ask for organ donation’. The film on wrong and right approach to family counselling was also played for the participants. Close to 150 participants attended the conference, consisting of doctors, nurses and transplant coordinators.

‘Starting deceased donation program’ by Ms Pallavi Kumar

Dr Pukar Chandra Shrestha felicitating Ms Pallavi Kumar

‘Panoramic view of the art work done by transplant recipients and others displayed at the conference’

Mrs Raghuram speaking on ‘Professional education opportunities in India’

Inspirational Leaders Award conferred on Mrs Lalitha Raghuram
Special Events

Rangoli Competition (உடற்பலட்சியானை) To Promote Organ Donation National Tollfree Helpline Number

A rangoli festival to promote organ donation was organized by MOHAN Foundation on January 21, 2023, in association with Chennai Metro Rail Limited (CMRL). The event was conducted at the Kathipara Urban Square (Zone 2), Chennai. This was the 4th edition of the rangoli festival organized in Chennai with the theme “Gift of Life through Organ Donation”. A total of 28 teams, comprising both adults and students participated in the event. Artists from different platforms expressed their support for the cause, and utilised the artform to spread organ donation message and National Tollfree Helpline Number. The event was visited by around 200 general public.

Ramp Walk For Life – An Initiative To Save Lives And Livelihoods

MOHAN Foundation celebrated its 25 years of saving lives through a unique “Ramp Walk for Life” wherein luminaries from various walks of life walked the ramp in Telangana Weaves and showcased their support for the cause on December 23, 2022. The event was held in partnership with Abhihaara Foundation which promotes Telangana Weaves.

Actress Revathy, who was the first celebrity to pledge for a donor card in 1997 when MOHAN Foundation was established, was the Guest of Honour. Ms Revathy flashed her “Donor Card” and sincerely appealed to the public to pledge for organ donation. She also spoke about her recent ventures Aye Zindagi and Salam Venky, which dealt with organ donation. She spoke highly of the challenging work performed by the transplant coordinators - approaching families for organ donation during their darkest hour of grief.

Doctors, celebrities, transplant recipients and donor families walked the ramp wearing Telangana weaves to create awareness on organ donation. The transplant recipients (organ and cornea) also narrated their hardships and how transplant changed their life.
A 3-week long campaign called “Zindagi Express” with the theme ‘Pass it on’ was unveiled by Edelweiss Tokio Life Insurance (ETLI) on January 5, 2023. This was the fourth consecutive year that MOHAN Foundation and Edelweiss Tokio Life Insurance had collaborated to spread the cause of organ donation. As part of the campaign, two canters named ‘Zindagi Express’ started their journey from Hyderabad and travelled through the west and east of India, stopping over at various cities while carrying the organ donation torch. A distance of 5,500 kms was covered, touring 62 cities, forming a ‘heart’ shape. The awareness drive came to a culmination at Bhopal, with a final flag off at the hands of Shri Vishwas Sarang, Minister of Medical Education, Madhya Pradesh. As part of the culmination, a relay marathon called ‘#PassItOnMarathon’ was held at Bhopal School of Social Sciences, in which more than 500 people participated.

**Impact of the campaign reaching 1 million+ people**

- Initiative reached 62 cities, 5 zones of the country
- Zindagi Express pitstop - Hyderabad, Mumbai, Nashik, Vadodara, Ahmedabad, Jaipur, Gwalior, Raipur, Ranchi, Patna, Lucknow & Bhopal
- Reached at least 8-language media - Hindi, Marathi, Telugu, Tamil, Kannada, Malayalam, Gujarati and Urdu
- Interacted with 500+ journalists across various beats in India
- Achieved 748 media impressions (Print, Online and TV)
- Achieved a PR Reach of 14,06,26,500 (14 Cr)
- Cumulatively, over the last 4 years, the life insurer has been able to reach 70 million+ people
Initiation of Organ Donation & Transplantation Program in Manipur
Pioneering Initiatives - A Glimpse

Consultative meeting on deceased organ donation at Jawaharial Nehru Institute of Medical Sciences (JNIMS), Imphal - December 8, 2022

Workshop on role of police in Medico-Legal Cases (MLC) in organ donation at Manipur Police Training Academy, Imphal - December 8, 2022

Organ donation awareness walkathon organized for the first time in Manipur - December 9, 2022