

INDIAN TRANSPLANT NEWSLETTER

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MULTI ORGAN HARVESTING AID NETWORK

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Editorial Desk**Evolution and Challenges of Pancreas Transplantation**

The pancreas has long been perceived as a formidable organ and it took the realm of pancreas transplantation nearly 30 years, from the experimental stage in the 1980s, to emerge as a standardized transplant procedure. The first pancreas transplant was performed in December 1966 by Kelly, Lillehi and Fredrick Goetz as a combined pancreas-kidney transplant procedure⁽¹⁾.

At present, pancreas or islet transplantation is recognized as the only cure for type 1 diabetes mellitus and certain cases of type II diabetes. The success of the pancreas transplant program has largely been due to improved techniques with a better understanding of how to avoid the complications of the surgery. This has resulted in continuing improvement in both short-term and long-term outcomes, as well as significant enhancements of quality of life, end-organ disease management with lower overall mortality⁽²⁾. However, the procedure's acceptance in India has been relatively sluggish.

India first ventured into pancreas transplantation under the stewardship of Dr. Sandeep Guleria at AIIMS, New Delhi. However, subsequent transplant procedures have been sporadic with only a few surgeons having performed this surgery.

This edition of ITN shares both global and Indian data on pancreas transplants. In 2021, India contributed 19 of the total 2025 pancreas transplants performed worldwide. Given that the total number of organ transplants was 144,302, pancreas transplants only constituted 1.4% of the total.

The year 2000 marked a significant breakthrough with the introduction of the "Edmonton protocol," a simpler and less complex method for successful solitary islet transplantation. Although this protocol has advanced from a theoretical concept to a viable treatment option for type 1 diabetes patients globally, its success has been limited due to limited number of pancreas donated and difficulty in maintaining the survival and function of the transplanted islet cells over time. Research is ongoing to improve the effectiveness and availability of this treatment, such as methods to grow large numbers of islet cells in the lab and the development of better immunosuppressive and anti-rejection therapies. This type of transplant will be a true game-changer when it is universally available and becomes the standard of care for diabetes.

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World Transplant Games 2023

The Transplant Games, which was first staged in 1978 in Portsmouth, United Kingdom, has developed into the largest awareness event in the world for the gift of life and a beacon for transplant recipients, their families, and supporters, donor families, and living donors. The 24th edition of the World Transplant Games (WTG) took place in Perth, Australia, from April 15 to 21, 2023. Athletes representing 45 nations competed in 17 distinct sporting disciplines.

Team India was represented by a group of 32 athletes, the highest number to ever represent India at the WTG. Notably, the Indian athletes achieved an unprecedented milestone by securing 35 medals, which stands as the highest tally ever attained by India in WTG.

During the Closing Celebration, the athletes' exceptional achievements throughout the Games were acknowledged and honoured with special awards established by the World Transplant Games Federation. The awards included

- The Greatest Gift Donor Family Award
- The Greatest Gift Living Donor Award
- The Inspiration of the Games Award
- Maurice Slapak Award
- The WTGF Outstanding Athlete & Outstanding Junior Athlete Award
- The WTGF Outstanding Team Award

The World Transplant Games presented the Outstanding Team Award to the team from the Islamic Republic of Iran, who achieved an incredible ratio of 5.36 medal points per athlete. This astonishing average equated to more than a gold and a silver medal for each athlete on their team.

Mr. Vijaybahadur Yadav from India was honored with the Greatest Gift Living Donor Award. This recognition was a result of his exceptional performance, including winning two gold medals in the 5K run and ball throw events, along with securing a silver medal in petanque.

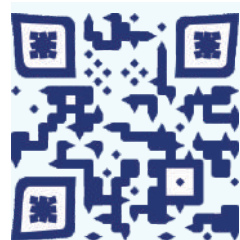
Cryopreserved Rat Kidney Transplant Performed Successfully By University Of Minnesota Researchers

Engineers and medical researchers at the University of Minnesota have demonstrated in a ground-breaking new study how rat kidneys can be cryogenically stored for up to 100 days. They rewarmed it using innovative nanowarming technique, cleared of cryoprotective fluids and nanoparticles and subsequently transplant them into rats, resulting in the restoration of full kidney function. The transplanted kidneys in five rats regained complete renal function within 30 days without the need for additional interventions.

A significant proportion of donated kidneys for transplantation each year gets wasted, primarily because these organs cannot be preserved with ice for more than 48 hours and subsequently failing to reach recipients within the required timeframe. Methods such as vitrification, which enable long-term cryopreservation, offer the advantage of allowing more time to find the optimal match between donor organs and recipients. Nevertheless, a significant challenge has been the difficulty in rewarming these cryopreserved organs without incurring substantial damage. The specialized

nanowarming process, pioneered by the University of Minnesota team, warms the organ rapidly and uniformly and not just at its surface.

"All of our research over more than a decade and that of our colleagues in the field has shown that this process should work, then that it could work, but now we've shown that it actually does work", said the study's co-senior author John Bischof, a Mechanical Engineering Professor and Director of the University of Minnesota Institute for Engineering in Medicine.



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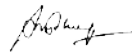
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Sd/-
Sunil Shroff
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Signature of Publisher



In Mann Ki Baat, PM Modi Emphasizes The Importance Of Organ Donation

In the 99th Episode of 'Mann Ki Baat' on March 26, 2023, the Prime Minister of India, Shri Narendra Modi, urged the people to support organ donation. In his speech, he stated that in the era of modern medical science, organ donation has emerged as a significant way to saving lives and that one "yes" may potentially save the lives of eight to nine individuals. He also added that it was gratifying to observe that awareness about organ donation was on the rise in our country and the families of those who have chosen to donate organs have indeed accomplished a great deed.

The PM also had conversations with the families of deceased organ donors during the Maan Ki Baat, including Sukhbir Singh and Supreet Kaur of Punjab who donated their 39-day-old daughter, Baby Ababat Kaur's organs; Abhijit Chowdhary, a resident of Jharkhand who donated the organs of his mother Smt. Snehlata Chaudhary.

He continued by saying that a large number of people are currently waiting for organ transplantation with the hopes of living healthy lives. Efforts are being made to create a unified policy across the nation in order to facilitate and promote organ donation. The need of a state's domicile has been eliminated, meaning that patients can now register for organ transplants in any state in the country. Additionally, the age limit of below 65 years for deceased donor transplant has also been removed. He concluded his message on organ donation saying, 'One decision of yours can save the lives of many people, can give life'.

The Organ Donation Flag Was Unveiled By The Chief Minister Of Rajasthan

The Chief Minister of Rajasthan Shri. Ashok Gehlot unveiled the organ donation flag on June 19, 2023, which was designed by MOHAN Foundation Jaipur Citizen Forum (MFJCF). The flag, bearing the message 'Gift of Life', aims to promote organ donation and honour the selfless donors and their families who have saved lives through their altruistic deed.

Mr. Rajiv Arora, the president of MFJCF, stated that the flag will be raised at two prominent locations in Jaipur: The Organ Donor Memorial near Central Park and the Eye Donor Wall in Bani Park.

Whenever an organ donation occurs in Rajasthan, as a sign of respect for the donor, the flag will be used to cover the donor's body before being handed over to the family. Before cremation, the flag will be removed from the body and then flown at the donor's home.

Additionally, the flag will serve as a symbol of identification for hospitals dedicated to encouraging organ donation. All organ transplant hospitals in Rajasthan will raise this flag to signify their commitment to the cause, as stated by Mrs. Bhavna Jagwani, the convenor of MFJCF.

The state has made a significant progress in organ donation since the first deceased donation in 2015. So far, 48 families have generously donated organs of their loved ones after they were declared brain dead resulting in 110 organs being transplanted to patients in need. This new organ donation flag is expected to further raise awareness and encourage more people to participate in this life-saving initiative.

Six Swap Kidney Transplants In Jaipur

In May 2023, the kidney transplant experts at Mahatma Gandhi Hospital (MGM), Jaipur, successfully performed swap kidney transplant in six patients. This exceptional event showcased the profound love and sacrifice of six families, resulting in a new lease on life for their loved ones. Although those patients with end-stage renal disease had willing kidney donors within their respective families, compatibility hurdles emerged. The exchange program involved recipients and donors from diverse family relationships, encompassing son and mother, husband and wife, wife and husband, and daughter and mother.

The kidney transplants were headed by Prof. Suraj Godara, Head of Nephrology, and Prof. TC Sadasukhi, Director of Renal Transplant Centre at Mahatma Gandhi Medical College & Hospital, Jaipur. As per the follow-up, the hospital reported that all the recipients and donors were doing well, and they were expected to resume their normal routines shortly.

Rajasthan Government Announced Rs. 1 Lakh Airfare For Organ Transplant Travel

The state government of Rajasthan announced Rs 1 lakh airfare for travel for patients and a family member travelling with them for organ transplant outside of the state. This was announced by the Chief Minister Shri. Ashok Gehlot as part of the state budget for the year 2023 - 2024.

The Chiranjeevi Health Insurance Scheme of Rajasthan encompasses a wide range of transplants, such as liver, kidney, lung, heart, bone marrow, and cochlear implants.

According to Ms. Shubhra Singh, Additional Chief Secretary, Rajasthan Medical and Health Department, this facility came into force from June 1, 2023. Additionally, beneficiaries who have already undergone organ transplantation in hospitals outside the state will also be eligible to receive compensation, in accordance with government packages. The guidelines included that only hospitals recognized by the National and State Organ and Tissue Transplant Organization will receive reimbursement for expenses related to organ transplant treatments.



Pancreas Transplant in India: Progress and Future



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Medical College & Hospital, Jaipur

Introduction

Diabetes is a major public health problem in both developed as well as developing countries. The global prevalence of diabetes is estimated to be around 11% amongst the age group of 20-79 years. Diabetes is one of the leading causes of chronic kidney disease (CKD) and end-stage kidney disease (ESKD) accounting for 50% of cases globally.^[1] Pancreas transplant offers the definitive cure for this disease. The first successful pancreas transplant was carried out by WD Kelly in 1966, refinements in surgical techniques and advancements in immunosuppressive therapy over last three decades have greatly improved the results and prognosis of pancreas transplant.^[2]

Pancreas transplant is the only treatment that helps to maintain euglycemia and prevents metabolic disturbances which frequently occur in type 1 diabetes patients that persists and even worsen in patients when only kidney transplantation is done. As more and more centres are offering simultaneous pancreas and kidney transplant, 1 year and 5 year survival rates are comparable to other solid organs transplantation.^[3]

Indications for pancreas transplant are^[4]

- Severe complications of diabetes mellitus with frequent and severe hypoglycemia or ketoacidosis.
- Poor quality of life in spite of insulin therapy.
- Patients with type 1 diabetes with end-stage renal failure on dialysis.

Various methods of pancreas transplantation are^[4]

1. Pancreas transplant alone (PTA)
2. Simultaneous pancreas and kidney transplant (SPK)
3. Pancreas after kidney transplant (PAK)
4. Simultaneous deceased donor pancreas and live donor kidney transplant

Table 1. Eligibility criteria for pancreatic transplant^[4]

Transplant type	Eligibility
Pancreas transplant alone	<ul style="list-style-type: none"> ● Insulin-treated type 2 diabetes mellitus with body mass index $\leq 30\text{kg/m}^2$ or ● Type 1 diabetes mellitus with at least two severe hypoglycaemic states within last 24 months and be specially assessed as having disabling hypoglycaemia
Simultaneous kidney pancreas transplant	<ul style="list-style-type: none"> ● Pancreas transplant alone requirements and ● Receiving dialysis or glomerular filtration rate $< 20\text{mL/min}$



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SPK is now the first choice of treatment in a patient with type 1 diabetes mellitus and related end-stage renal disease. Pancreas alone transplant can be done in patients with preserved kidney function and hypoglycaemic unawareness.^[5]

Islet Cell Transplant

The incidence of islet cell transplantation have reduced after discovery of insulin. There was a realization that apart from the inconvenience of repeated glucose measurements and insulin injections, many patients still had to face the major complications of diabetes. The regimen followed for islet cell transplantation is "Edmonton Protocol" which consists of transplanting an adequate islet mass sometimes from sequential donors ($> 10,000$ islet equivalents per kg recipient body weight), immediate infusion of the islets following isolation, and avoidance of corticosteroids. As in whole pancreas transplantation, the islets can be transplanted alone or after kidney transplantation.^[6]

Pancreas Transplant in India

About 1000 pancreas transplants are performed in the USA each year. In contrast to this, less than 100 such transplants have been performed so far in India. At present, only a few centres across the country offer pancreas transplant on a regular basis including Mahatma Gandhi Medical College & Hospital, Jaipur.^[7]

The reasons for lack of pancreas transplantation in our country has been the lack of availability of deceased organ donors. This situation is changing fast with over 900 deceased organ donation in 2022.^[7]

Challenges in Indian Settings at Present

Although there is an increase in number of deceased organ

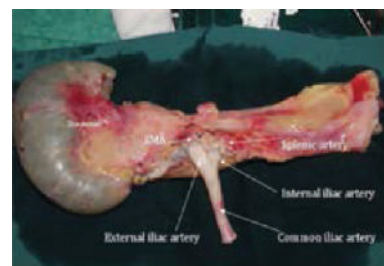


Figure 1 (a) Explanted pancreas specimen after reconstruction



Figure 1 (b) Implanted pancreas

donors in India, the number of pancreas transplants are still low. This is because unlike kidney and liver, only a small proportion of all donated pancreas' can be used for transplantation, as criteria for pancreas suitability for transplantation are very stringent like age limit between 10-45 years, obesity etc.^[7]

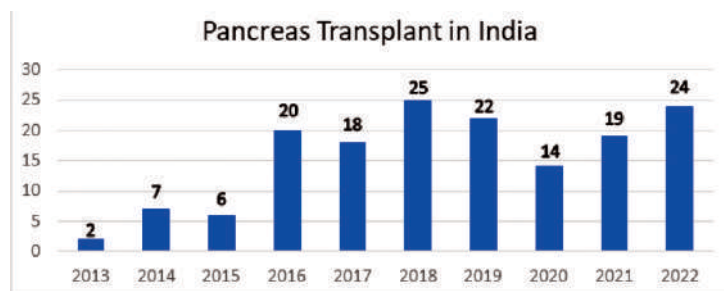


Figure 2 depicting total number of pancreas transplants in INDIA from 2013-2022.^[8]

Future in pancreas Transplant

Segmental pancreas transplant from live donors has also been reported. The success of this concept potentially bypasses the issues surrounding organ shortage for waitlisted patients in the same way as in live kidney/liver transplant. With technological advancement, the new devices to improve blood glucose monitoring and insulin therapy are being developed to reduce the risk of wide fluctuations in blood sugars. An artificial pancreas also known as closed-loop insulin delivery systems use a continuous glucose monitoring that measures interstitial glucose concentration, an insulin pump, and a control algorithm to calculate insulin dose and maintain normoglycaemia without user input.^[9]

Other Recent Advances in Pancreas Transplant

Advances over the last decade suggest that generating functional beta-cells from stem cells is achievable. However, there are aspects of beta-cell development including the signalling pathways that instruct endocrine progenitor cells to differentiate into mature and

functional beta-cells which remain poorly understood. These ideas combined with ideas of biological printing using the extracellular matrix as a scaffold to recreate a new biological pancreas are exciting, and although have their own challenges may change the way transplant is performed.^[10]

Conclusion

Pancreas transplant in association with simultaneous kidney transplant is growing and has quickly become the gold standard of care for patients with type 1 diabetes mellitus and renal failure. Significant improvements in quality of life and increase in life expectancy make pancreas transplant an economically viable option. It remains the most effective method of establishing and maintaining euglycemia, halting and potentially reversing complications associated with diabetes mellitus.

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Pancreas transplants from different regions of the world

	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
United States of America	1082	1043	1018	954	947	1013	1002	1027	1015	962	963	–
United Kingdom	236	254	264	239	244	206	202	217	185	116	137	146
Brazil	184	151	163	140	121	134	111	150	177	148	162	133
Germany	171	161	128	120	105	97	72	95	94	92	65	44
Spain	111	83	92	81	97	73	70	82	76	73	82	92
Canada	108	72	77	77	76	95	76	57	69	57	53	–
Argentina	75	68	76	69	74	48	62	89	74	48	39	36
France	73	72	85	79	78	90	96	78	84	34	67	70
Italy	58	67	59	43	50	67	39	41	42	41	54	38
Australia	26	38	33	45	45	51	49	51	40	47	37	–
India	–	–	2	7	6	20	18	25	22	14	19	24

Source: <https://www.transplant-observatory.org/> (As on June 30, 2023)



Workshop on “Strengthening Organ Donation & Transplant Processes in Manipur” with Jawaharlal Nehru Institute of Medical Sciences (JNIMS), Imphal



Release of “Manual on Brainstem Death & Deceased Organ Donation”

On April 01, 2023, MOHAN Foundation in association with Jawaharlal Nehru Institute of Medical Sciences (JNIMS) conducted a workshop on “Strengthening Organ Donation & Transplant Processes in Manipur” which was attended by about 140 participants.

The objectives of the workshop were to give participants the necessary knowledge and skills to address the various aspects of brain-stem death certification, maintenance and deceased organ donation, and to provide a roadmap for hospitals planning to start deceased organ donation and transplantation program.

Dr. Sapam Ranjan Singh (Hon'ble Health Minister, Govt. of Manipur) was the Chief Guest at the program who affirmed that he



Ms. Pallavi Kumar moderating panel discussion

would walk the extra mile and extend all possible help, within the ambit of the law, to make kidney transplantation successful in the state of Manipur.

Prof. L. Deben Singh (Director, JNIMS) in his presidential address stated that living donor renal transplants in a government-run hospital like JNIMS is a boon to society.

The faculty for the workshop included Dr. Sunil Shroff (Managing Trustee, MOHAN Foundation), Ms. Pallavi Kumar (Executive Director – Delhi NCR, MOHAN Foundation) & Prof. Deepak Gupta (Professor – Dept. of Neurosurgery, AIIMS, New Delhi).

The workshop also included panel discussions on 'Caveats in Brain Death Identification and Certification in a Hospital' and 'Corneal Donation and Transplantation in Manipur'.

State Organ & Tissue Transplant Organization (SOTTO), Haryana, celebrates “Naman Diwas” in collaboration with MOHAN Foundation

The State Organ & Tissue Transplant Organization (SOTTO), Haryana, in collaboration with the MOHAN Foundation, celebrated "NAMAN DIWAS" on April 15, 2023 at Pt. B. D. Sharma Post Graduate Institute of Medical Sciences (PGIMS), Rohtak. The event was organized to honour the organ, tissue, and body donor families as 'REAL Heroes' for their extraordinary act of courage and to serve as a model for others to emulate and promote organ donation.

The act of generosity displayed by 57 donor families was acknowledged and honoured during the event. The Chief Guest, Dr. H. K. Aggarwal, Registrar, Pandit Bhagwat Dayal Sharma University of Health Sciences, said that it was a matter of great pride to honour the posthumous organ donation family. The decision taken by the government to honour these families who donated the organs of their family members on Naman Diwas was commendable.



Felicitations of families of organ donors and body donors

Workshop at Dr. Mehta's Hospitals, Chennai – April 2023



Dr. Sunil Shroff discussing the legal framework of deceased organ donation and transplant in India

Dr. Mehta's Hospitals in association with MOHAN Foundation organized a workshop on "Deceased Organ Donation" on April 29, 2023, at the Dr. Mehta's Hospitals, Chennai. The workshop aimed to educate healthcare professionals, including doctors, nurses, social workers, and technicians, on various aspects of organ donation.

Dr. Sukanya, Govindan, Nephrologist, Dr. Mehta's Hospitals gave an overview about the workshop. Dr. Sunil Shroff, Managing Trustee, MOHAN Foundation discussed the legal framework of deceased organ donation and transplant in India. He emphasized the legal provisions and guidelines to implement the deceased donation program in a hospital.

Followed him was Dr. Raghavendran, Professor of Neurosurgery, Madras Medical college and Rajiv Gandhi Govt. General Hospital who talked about the identification and certification of brain stem

death. His lecture covered the concept of brainstem death, testing for brainstem reflexes, conducting apnoea test and interpreting results. He also briefed about scenarios where apnoea test shall not be conducted and role of ancillary tests in such situations.

The workshop included a session on maintenance of a potential brain-dead donor in the ICU by Dr. Ponniah Vanamoorthy, Head, Department of Neurocritical Care, Neuroanesthesiology, Kauvery Hospital, Chennai. He also explained the donor management goals and case scenarios.

Mr. Johnson A, Transplant Manager, Apollo Hospitals, Chennai was the faculty for the session on counselling the grieving families. He spoke about the various stages of grief, counselling process and do's and don'ts in counselling.

The workshop included activities on the following

- Brain death and organ donation
- Simulation – Approaching families for organ donation
- Deceased organ donation – Process & protocol



Mr. Johnson A, briefing counselling for organ donation in medico-legal cases

Workshop at Narayana Health, Bengaluru – May 2023



Dr. Akhila Vasanth, Pediatric Nephrologist, Narayana Health felicitating Dr. Theepeswamy Veerasha. Mr. Shridhar, Honorary Director, MOHAN Foundation-Bengaluru (right) is also seen in the pic

MOHAN Foundation and Narayana Health in collaboration organized a workshop on 'Deceased Organ Donation' at the Narayana Health City, Bengaluru on 5th May, 2023. The workshop was supported by the SBI Foundation and SBI Card. About 100 participants attended the workshop including doctors, nursing staff, technicians and also medical and para-medical students.

The workshop covered various topics such as deceased organ donation and the legal framework in India, Brainstem death – identification and certification, Counselling the grieving families and making the ask for organ donation.

Ms. Sujatha Suriyamoorthi (Associate Director – Courses), MOHAN Foundation delivered the talk on 'Legal framework of deceased organ donation and transplant in India'. She discussed about the transplant law in the country, their amendments and brainstem death and provisions for donation after brainstem death. In

addition, she also spoke about the licensing process for hospitals under the Transplantation of Human Organs Act.

Followed by her talk, Dr. Sunil Karanth, Head, Critical Care Medicine, Manipal Hospitals, Bengaluru talked about brainstem death. He stressed the importance of early identification and medical management of potential brain dead donors in ICU.

Dr. Theepeswamy Veerasha, Transplant Coordinator, Institute of Gastroenterology Sciences and Transplant, Victoria Hospital Campus, Bengaluru was the speaker for the session on counselling grieving families. He is an inspiration for many not only in the field of transplant and organ donation, but also in the wheel-chair cricket category. He spoke about the various stages of grief, counselling process and dos and don'ts in counselling.

The workshop included few activities organized by MOHAN Foundation to make the session more interactive and provide clarity and better understanding about the deceased donation and steps involved in medico-legal cases. Students had an active participation and enjoyed the role plays conducted on approaching families for organ donation.



An activity on brainstem death and organ donation, moderated by Ms. Sujatha Suriyamoorthi

With 35 Medals at the World Transplant Games, Team India Makes Waves Down Under



Team India at Perth

In April 2023, after 18 months of preparations the largest contingent of athletes, Team Management and Support Staff – 32 athletes, 2 support staff, 5 Team Management, 3 volunteers – took off from India and headed to the World Transplant Games 2023 at Perth, Australia. Breaking all previous records, Team India made a splash at the World Transplant Games, winning 35 medals, and came back to magnificent receptions in their various cities and communities! Participation in transplant sports is a tremendously effective way to raise awareness amongst the public and we hope to take a bigger team to Dresden, Germany in 2025.

For many years, India's participation at the Games was mostly driven by the athletes themselves. Teams of 2-3 athletes have been participating, and winning medals since at least 2011, but the change came in 2019 when Light A Life – Reena Raju Foundation took a 14 member contingent to the WTG 2019. That set the stage for 2023, when ORGAN India became the official Member Organization and Team Managers for India for the World Transplant Games 2023.

The Team

In all, 32 athletes participated in the Games, consisting of 24 organ recipients and 8 organ donors/donor family. This included 3 heart recipients, 17 kidney recipients and 4 liver recipients. A medical team Dr. Deepak Bhatia – Orthopaedics, Mumbai, Dr. Jo Joseph, Kerala, Heart Transplant Surgeon, and Mr. Manjeet Kumar – Physiotherapist travelled with the team.

Mr. Karhun Nanda, a heart transplant recipient and golfer, was appointed by the team management as Team Captain and proved to be an invaluable asset. Mr. Vijaybahadur Yadav, a fantastic donor athlete was de facto coach while at the Games. He was also Donor Athlete of the Tournament at WTG 2023!

The athletes were from across India but concentrated in large cities in the North and South. Athletes from Kerala, Karnataka, Rajasthan and Delhi were represented in considerable numbers. Representation from Western states was less than was expected and sadly, there was no participation from the Eastern States.



Opening Ceremony

Regrettably there was only 1 female recipient athlete, Merlyn Paul from Kerala. This highlights both the disparity between female/male recipients as well as the under-representation of women in sports in India. Conversely, women were considerably well-represented in the donor category, with Ankita Shrivastava, Mili Tony, Deepa, and Maggie Paul, as women in India are massively over-represented when it comes to living donation.

We also had a junior athlete for the first time ever! 13-year-old Varun Anand from Bangalore bagged 3 gold medals in tennis, table tennis and badminton!

Partners

Considerable financial support was required for the entire project. A major fundraising campaign proved fruitless. Eventually, several Trusts and corporate organizations like Dinesh Vyas Trust, Geekay Winding, To The New, and EXL came forward. **Regrettably, no healthcare stakeholders supported the project.**

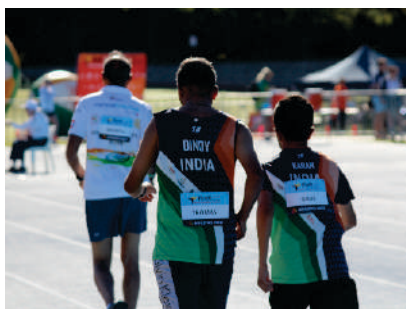
To ensure the best allocation of any funds received, a Resource Allocation Committee was created to disburse funds consisting of ORGAN India representatives, a former national level athlete, transplant doctors, a sports journalist, and the Team Captain.



Javelin competitor Heera Singh Daspa (Gold Medalist)



Press event in Delhi



Dinor & Karan – Athletic Events



Athletes from Team India

We were fortunate enough to find a partner for technical, nutritional, and psychological training in this endeavour, in the form of Dr. OP Bhalla Foundation and Manav Rachna Group of Institutions, through their dedicated Sports Science Center in Faridabad. Manav Rachna hosted 2 separate camps in August 2022 and March 2023. Around 20 athletes attended each camp.

The camps were invaluable as they also provided a meeting ground for team members to meet and bond prior to the Games. The Team India was a more cohesive unit, thanks to this opportunity.

Visa Issues

After much documentation, 8 visas were refused, with the common reason that the applicant had failed to prove they would return to India. Team management urged the organizers to intervene with the Australian government. The organizers were extremely helpful and all 6 athletes who re-applied were granted visas. It's worth mentioning that all 6 came back with medals!

Team Management

A 5-member coordination team from ORGAN India travelled with the athletes to provide logistical and administrative support to the athletes and ensured that an ORGAN India representative travelled with all athletes who were travelling for the first time. Team Management coordinated daily the transportation to and from venues for the athletes and barring one day, team managers were present at all the venues.

The team from ORGAN India included: Sunayana Singh (Country Representative), Shankar Arora (Team Manager), Anika Parashar (Chairperson, Parashar Foundation), Aprajita Verma, Dr. Sourabh Sharma, Eeda Gujral Chopra, Inayat Puri, and Zoravar Singh.



Vijaybahadur Yadav winning gold in 5Km open run

Outreach and Public Relations – A social media and PR campaign was launched a year prior to the event, leveraging the considerable social media reach of ORGAN India to spread awareness about the Games. Pre-departure and post arrival press events were held where athletes and team management engaged with media persons.

There was a collaboration with Whistling Woods International, Mumbai to create a special team song, entitled 'Hissa Bann', sung by Raag Suri.

After 10 years of working relentless in the field, including extensive awareness activities throughout the country, we realized that people still view organ donation and transplant with some degree of uncertainty, and are largely unaware of the positive outcomes of organ donation and transplant. We felt India's successful and well-organized participation at the World Transplant Games would demonstrate the country that not only is organ donation a wonderful gift to others, but that transplant recipients can go on to lead extremely healthy, fit and happy lives. This aspect of organ donation needs to be highlighted and there was no better way than to do it through excellence in sports – an aspect of our lives which brings about feelings of patriotism, joy, and positivity.



Master Varun bagged 3 gold medals at the WTG 2023

Our 32 amazing athletes have done just that!

Sunayana Singh
CEO, ORGAN India, Parashar Foundation
Country Representative (India) –
World Transplant Games Federation



"In the generous act of one, my life found a new dawn. To my unknown hero, with every heartbeat, I am overwhelmed with gratitude."

Karishma Mistry (28 years), New York

I was born with a liver disease called biliary atresia which led me to having a liver transplant. I always knew I would need a transplant but the timing of it was unknown. Getting a transplant as a newborn is extremely tough and finding a donor is equally as difficult, so we hoped my health could be managed until I was older and stronger.

Growing up I was a relatively healthy and normal kid; besides the fact that I had to take medications, no one could tell I had an illness or was any different. At the age of about 10, my health started to severely deteriorate, and it was determined that I was nearing my time and needed a new liver. I was put on the transplant waiting list on March of 2006 and we started our search for a potential donor. Unfortunately, out of my family members and close friends who were willing to donate, no one was a perfect match; my mother was only a partial match, and we did not want to risk a possible rejection. So, all we could do was hope, pray, and wait for some miracle to happen.

Luckily, one night at the end of May we received a phone call stating that they may have found a perfect liver match for me. We tried not to get our hopes up as after more thorough testing, the donor, who was a deceased donor, may not turn out to be a match for me but initially the prospect looked promising. We quickly packed up the car as my transplant center was a 3-hour drive away from my home and started the journey to what could be a new life for me. Upon my arrival, we did all the testing and a few hours later it was final that this donor was a perfect match for me. After what felt like a never-ending cycle of gaining and losing hope since my childhood, one transplant, six days in the intensive care unit, and twenty-eight hospital days later, I was given a second chance at life.

Leading a Normal Life

Since then, I have been an extremely normal and healthy child; I started school again and was living just as any other kid my age. I have been lucky to not have any complications post-transplant and am on just a minimal dose of immunosuppressant medications. By keeping up with my medications, eating healthy, and exercising, I am no different than any other person and am able to live a normal life. After much thought and a long road, I also decided to pursue

medicine as my career path. I am now in my final year of medical school and am going to be a doctor in just a few short months!

Ambassador for 'Gift of Life'

Once I got older, I understood the reason I am alive today was because someone decided to donate their organs after death. This led me to get increasingly involved with promoting organ donation with different organizations in the USA such as Donate Life America and more recently with MOHAN Foundation in India. My work throughout college with LifeSource consisted of giving talks to nursing students, educating high school students on what organ donation means, and sharing my story with other healthcare professionals at various events throughout the area. Most recently, I was invited by MOHAN foundation to talk to fellow transplant recipients and share my story on how I have managed to live an absolutely normal life and continue achieving my dreams without fear.

Furthermore, in medical school, I realized there was no formal learning objective on organ donation in the USA and Canada. After many meetings and talks with our education board, I was able to get the topic of "organ donation" added as an objective for all medical students at my school. I continue to spread the word of organ donation on social media constantly.



Karishma with her father

I have been so fortunate in my entire journey and am lucky to have had two doctors as parents taking care of me as well. Without the support of my family and without the intention of someone to donate their organs, I would not have been able to survive to this stage in my life. I will forever be grateful for my donor and for the chance to continue my life. I hope that in my future career as a doctor I am able to continue to spread my story to increase awareness for organ donation while also connecting with recipients and empowering them to achieve their dreams and goals.

Shattering Taboos in Society – An Ambassador's Journey

With no qualification in the medical or legal field and with no history of organ donation or transplant in my circle of family and friends, I decided to dedicate my post-retirement life to spreading organ donation awareness. Since there was no single moment or incident attributable to my decision, I can think of it as 'Serendipity' or 'Maktub' (It was destined – Ref. Paulo Coelho's Alchemist).

I pledged my eyes way back in 1985, and after almost 3 decades later, I pledged my organs & tissues. During this time period, I educated myself and was deeply impressed by MOHAN Foundation's multifarious humanitarian and altruistic activities.

I relocated to Nagpur, my home town, in 2019. On finding MOHAN Foundation's office, just a few blocks away from my residence, one day I simply walked in and met Dr. Ravi Wankhede, Hon. Director of MOHAN Foundation, Nagpur. He was also a leading member of Zonal Transplant Coordination Committee, Nagpur and a doyen of Organ Donation in the region. His unwavering commitment and high level of involvement in activities to further the cause of organ donation had a profound effect on me. That visit changed my entire perspective of life. I realized that I had found my life's 'Will to Meaning' (Ref. Victor Frankl).

Soon I completed MOHAN Foundation's 'Gift of Life' course, got enrolled as a Life Member, and started conducting organ donation awareness sessions independently. Later, I successfully completed the course on 'Legal Aspects of Organ Donation & Transplantation' which gave me a holistic view of the organ donation and transplantation process. During this time I also received tremendous encouragement and support from members of ZTCC, Nagpur.

During COVID-19, I hosted webinars on organ donation awareness. Post-COVID, I started conducting awareness sessions at various places including IIM, Symbiosis, Dr. Ambedkar College Department of Law, Tirpude College of Social Work etc. In addition, I have assisted ZTCC in organizing events in support of organ donation and amplifying their events.

In the course of performing my role as MOHAN Foundation's Ambassador, I have realized that organ donation is a very sensitive and personal matter. It is best to provide people with comprehensive



Mr. Devang Chhaya, Organ Donation Ambassador, Nagpur

understanding about the subject (process, legal aspects, ethical issues etc), appeal to their humanitarian sense and leave them free to make an informed decision after consulting their family. We must also shatter the taboo of not discussing death and encourage conversations on planning for post-death scenario similar to post-retirement scenario. This will help develop a mindset which would be receptive to the idea of organ donation.

By engaging and interacting with my audiences, I have realised that organ donation remains mired in misconceptions, myths and superstitions. A large number of our population still carries an impression of scams in trading of organs in living donation cases. Unfortunately, our movies and social media still continue to reinforce the misconception regarding organ trade under the garb of jokes in poor taste.

My journey as an Organ Donation Ambassador of MOHAN Foundation has been extremely fulfilling and gratifying. It has given me a golden opportunity to make a positive impact on people's lives and has provided a sense of personal motivation to continue advocating for this cause.

The journey has just begun. I fully realize the enormity of the task before me and acknowledge that I have miles to go....

The 2023 Florence Nightingale Awardee Is The Proud Organ Donation Ambassador

Ms Madhavi Rane Chikale while working at the BJ Wadia Hospital underwent the Organ Donation Ambassador volunteer training in June 2021. As an ambassador, she motivated many of her nursing staff to join the volunteer training. 35 nurses of BJ Wadia Hospital signed up for the Ambassador training. In June 2023, the hospital registered its first paediatric donation.

As an ambassador Madhavi motivated others by participating in the Pinkathon in Mumbai. Her group of volunteers and friends wore pink sarees and explained the concept for organ donation to other runners. She also organised a women's football match to promote organ donation. She later shifted to Mohali and continued her awareness activities through the hospital. Recently in Chandigarh she conducted an awareness event 'Cycling in

Nauvari Saree' – the traditional attire of Marathi women.

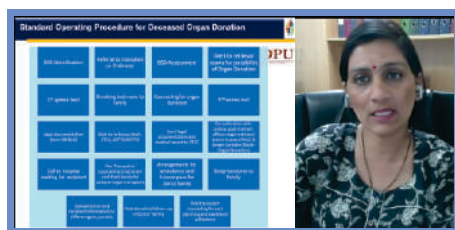
She feels that there is a great shortage of nurses, and so it falls upon them to take up health issues to educate the public. She was honoured with the Florence Nightingale Award for her work on June 22, 2023 by the Honourable President of India, Smt. Droupadi Murmu at the Rashtrapati Bhavan. She said that this recognition is for her teachers and mentors and the families of patients who have given her encouragement to work in the field of nursing.

MOHAN Foundation is proud to have her as an Ambassador.

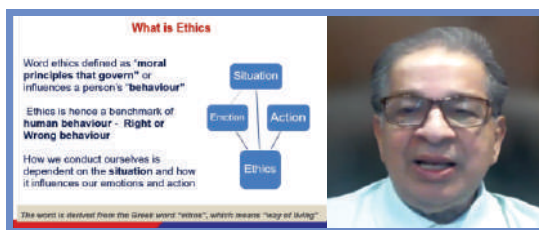


Ms. Madhavi Rane Chikale receiving the Florence Nightingale Award for 2023 from the President Smt. Droupadi Murmu.

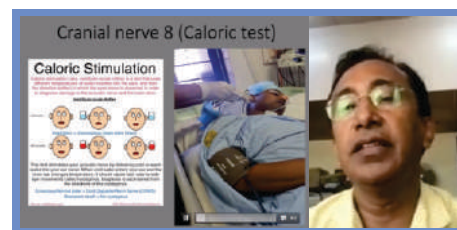
Online Course on Transplant Coordination Professional Certificate



Mrs. Mayuri Barge, Manager – Organ Transplant Program, Dr. D. Y. Patil Hospital (Pune) talking on 'Standard operating procedure for deceased organ donation' – May 2023



Session on 'Ethics aspects of organ donation and transplantation' by Dr. Sunil Shroff, Managing Trustee, MOHAN Foundation – June 2023



Dr. Eshwar, Professor and Head, Department of Neurosurgery, Sree Chitra Tirunal Institute for Medical Science and Technology, Trivandrum explains cranial nerve assessments in brain dead patients – June 2023

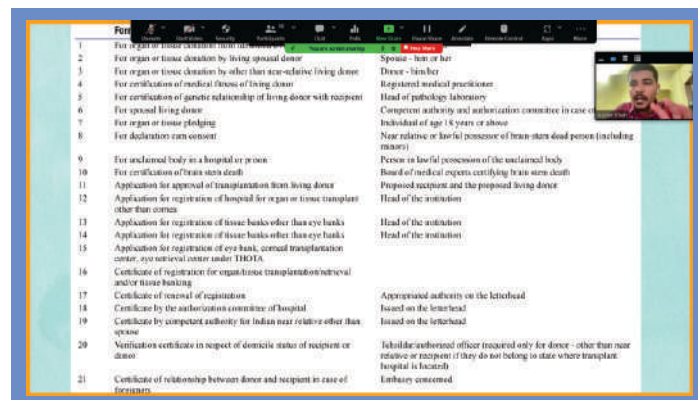
A short-term online course on 'Transplant Coordination Professional Certificate' was successfully conducted by MOHAN Foundation. Two batches were trained during the period from March 2023 to June 2023. The course was designed with online modules and interactive webinars to create an engaging and informative learning environment for the participants.

The webinars focused on

- Basic concepts of organ donation and transplantation
- Transplantation of Human Organ Act, Rules and Amendments
- Role of a donor coordinator in deceased organ donation and documentation
- Approaching families for organ donation and case studies
- Living donor transplant coordination – Role of a transplant coordinator
- Role of a transplant coordinator in recipient coordination (Heart and Lung Program)
- Ethical considerations in organ donation

March 2023 – June 2023

61 candidates were trained from India, Botswana, Ghana, Nepal



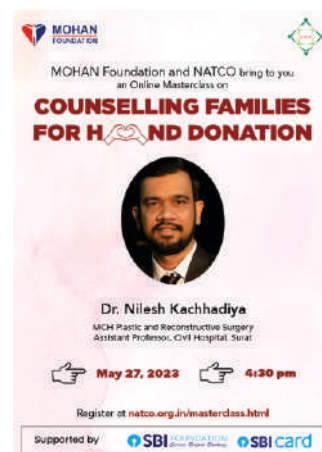
Mr. Haider Ali Khan, Liver Transplant Coordinator and Grief Counsellor, Care Group of Hospitals, Hyderabad explaining list of documents involved in living donor transplant program – May 2023

Masterclass

Supported by the SBI Foundation and SBI Card In Collaboration with the Network and Alliance of Transplant Coordinators (NATCO)

Counselling Families for Hand Donation

Hand transplants are superior to prosthetic hands, especially in the case of bilateral hand amputees. Even though challenging, the bigger problem for hand transplants, is the lack of families consenting to donate hands of the deceased.



The objective of the masterclass on "Counselling Families for Hand Donation", held on May 27, 2023 was to equip the participants with counselling skills that would help the families make an informed decision regarding hand donation. Dr. Nilesh Kachhadiya, an Assistant Professor at Civil Hospital in Surat, was the faculty who got consent for multiple hand donations from brain dead donors in his hospital. Hand transplantations in India and their challenges was also discussed during the session.

Mental Health – Before and After Transplant

On 17th June 2023, a webinar conducted on 'Mental Health – Before and After Transplant' was attended by organ recipients, donors, caregivers, patients on dialysis, transplant coordinators.

The session was conducted by the panellists from MindSmith, Dr. Satyen Sharma, a Senior Consulting Psychiatrist & the Founding Director along with Ms. Sindhu Wadhwa, Head of Therapy at the MindSmith & a renowned Psychotherapist with over 14 years of experience. The webinar aimed to raise awareness about the mental health challenges surrounding organ transplantation, validating and supporting the participant's emotions. The webinar highlighted the emotional journey individuals undergo during the transplant process and stressed the importance of identifying early signs of depression in both oneself and others.



Making Transplants Affordable – An Initiative By MOHAN Foundation

“Anudaan – Making Transplants Affordable” is an initiative launched by MOHAN Foundation in 2021 as a mark of its journey towards saving lives since 1997. This initiative aims to provide financial assistance to the economically underprivileged, thus enable access to life-saving transplants. Most transplants take place in private sector hospitals and the prohibitive costs makes 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. Between March 2023 – June 2023, ten 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.

Anudaan acknowledges below individual contributions for joining hands with MOHAN Foundation's initiative towards making transplants possible to the less affordable.

Mr. Jairam Balakrishnan

Ms. Rekha Kumar

Anudaan received a generous grant from **Mr. Adi Dasika and his wife, Lakshmi** enabling the support towards many more transplants for children from economically underprivileged families. Mr Dasika is the founder and president of Icon Technologies and also a board member of MOHAN USA. He has personally witnessed the problems of patients with end-stage organ failure and the benefits of organ transplantation as his mother-in-law underwent a kidney transplant. This experience inspired the couple to dedicate their retirement towards raising awareness on organ donation. They have helped organize many fundraisers to benefit organ failure patients.

MOHAN project

An initiative touching lives...



PARENTS WANT HIM TO BE A
PROFESSOR
MASTER CHETHAN KM
3 yr, Kolar, Karnataka
Liver Transplant on March 7, 2023



MR. MONISING BUNGDON
61 yrs, Chandel, Manipur
Kidney Transplant on April 7, 2023



PARENTS WANT HIM TO BE A
BUSINESSMAN
MASTER ADVIK AMBADGATTI
1 yr, Dherwad, Karnataka
Liver Transplant on March 28, 2023



ASPIRES TO BE A
ENTREPRENEUR
MR. LAIMUJAM PREMJIT SINGH
44 yrs, Imphal, Manipur
Kidney Transplant on March 7, 2023



PARENTS WANT HER TO BE A
DOCTOR
BABY DARSHITA ZORE
1 yr, Buldhana, Maharashtra
Liver Transplant on April 24, 2023

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

अनुDAAN
Making Transplants Affordable



PARENTS WANT HER TO BE A
SURGEON
BABY DIVYA NAMDEV JADHAV
8 months, Bider, Karnataka
Liver Transplant on May 23, 2023



ASPIRES TO BE A
POLICE OFFICER
MASTER MOHAMMED HUSSAIN
10 yrs, Bengaluru, Karnataka
Liver Transplant on May 3, 2023



ASPIRES TO BE A
SOFTWARE ENGINEER
MASTER VRUSHANK PATIL
9 yrs, Raigarh, Maharashtra
Liver Transplant on April 13, 2023



ASPIRES TO BE A
TEACHER
MASTER RAMESWAR BALU SANGALE
16 yrs, Nashik, Maharashtra
Kidney Transplant on April 11, 2023



ASPIRES TO BE A
CRICKETER
MASTER BHASKAR V
13 yrs, Raichur, Karnataka
Liver Transplant on May 6, 2023

“Through organ donation, one soul's ending becomes another's beginning – it's the ultimate gift of life.”



A Conversation That Can Save Lives: Family Conversations And Its Influence On Organ Donation

Siri Gurram, Nived Devadas, Ridhi Singhania, Rishika Kedia

Faculty Guide: Jitendra S Rajput

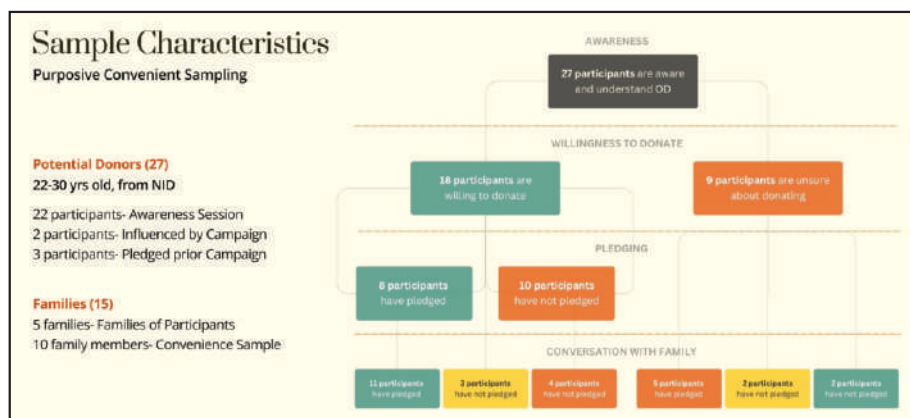
Strategic Design Management, Master of Design

National Institute of Design, Gandhinagar

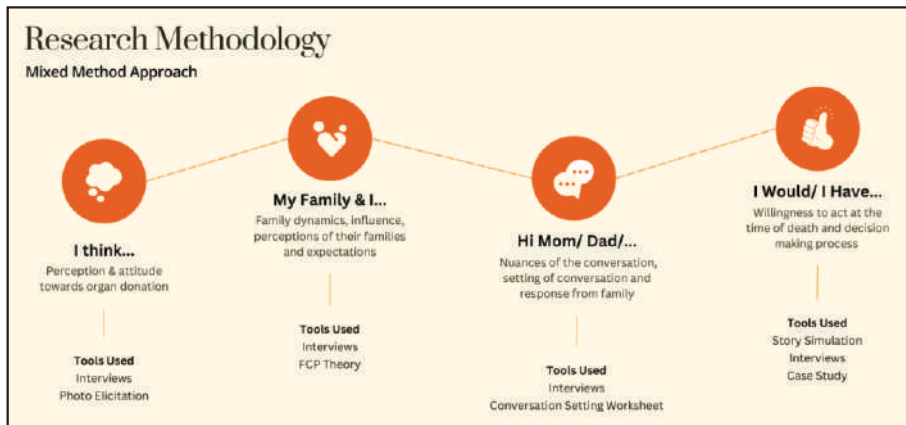
India has made commendable progress in organ transplantation, experiencing a 27% annual increase in transplant numbers.¹ However, this achievement continues to be overshadowed by the prevalence of live organ donations, which necessitate life-altering procedures for healthy individuals who decide to donate. A crucial factor contributing to this disparity is the final decision-making authority resting with the family of a potential donor in case of deceased organ donations, regardless of whether the individual had previously pledged to donate. During times of grief, the concept of organ donation presents an unexpected challenge and adds a layer of pressure on decision-making. This emotional burden can potentially lead to a rejection of donation, especially when the topic has never been addressed within the family.

According to a study by Siminoff et al. (2001), prior knowledge of a patient's wishes significantly ties to the family's willingness to donate and families who have more conversations about organ donation are more likely to donate.² However, the stark reality is that a significant number of families avoid discussions about organ donation, and likewise, many registered donors fail to communicate their intentions to their loved ones, leading to organs going unutilized when the opportunity arises.

This research conducted by the students from the National Institute of Design, Gandhinagar as part of their Design Project, aims to study the influence of family in the process and how family conversations and dynamics shape the decisions regarding organ donation.



Sample characteristics of the research participants



Research methodology and qualitative tools used in the process

Please note that some limitations of the study include the sample being limited to students from the National Institute of Design, Gandhinagar and their families, which is not an accurate representation of the entire population of the country. The time constraint of 6 weeks prevented the study from examining real-life scenarios with respect to the conversion of pledges. A few participants were reluctant to share openly due to the topic's sensitive nature.

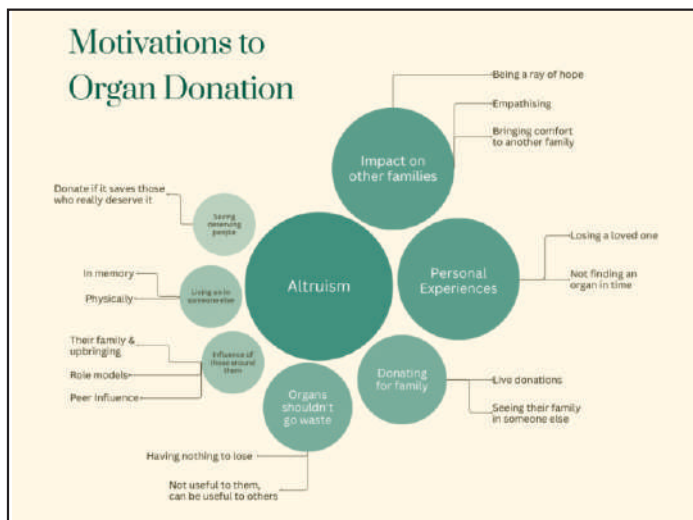
The key outcomes that emerged from the study are –

Individuals who were exposed to the concept of organ donation through examples in their community or had family members who set a precedent of giving back to society were more inclined to make pledges or engage in conversations with their families.

The research also revealed a **disconnect with the term "organ donation"** itself. The word "organ" carries a scientific connotation, emphasizing the procedural aspects and potentially overshadowing the emotional experience of the families involved. Conversely, "donation" typically implies a charitable act arising from a sense of abundance and satisfaction. However, in the context of organ donation, families endure profound personal loss, resulting in a deep association with death rather than life. As a result, the notion of a "celebration of life" is not well-received in cases of untimely death. Hence, there is a need to reconsider the terminology.

India being a collectivist society, individuals have a **strong sense of ownership and attachment towards their family**, including their bodies. There is an inclination to conform to their family's norms, both overt

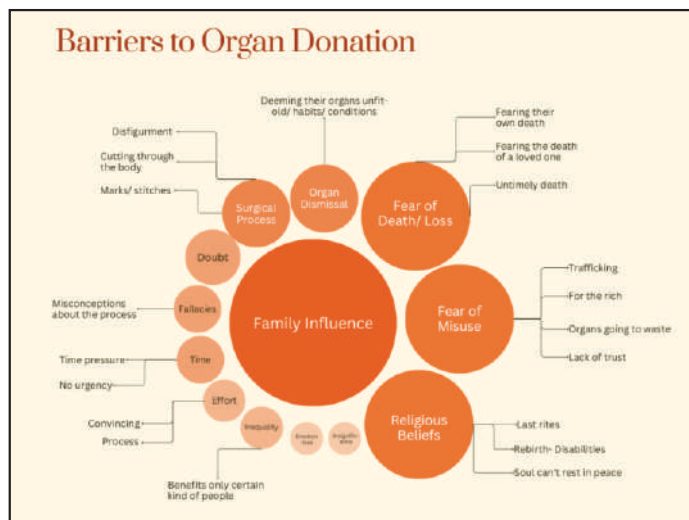
1. India saw record over 15,000 organ transplants in 2022: Union Health Secretary. (2023, February 19). India Saw Record Over 15,000 Organ Transplants in 2022: Union Health Secretary – the Hindu. <https://www.thehindu.com/sci-tech/health/india-saw-record-over-15000-organ-transplants-in-2022-union-health-secretary/article66528816.ece>
2. Siminoff, L. A., Gordon, N., Hewlett, J., & Arnold, R. M. (2001). Factors influencing families' consent for donation of solid organs for transplantation. *JAMA: Journal of the American Medical Association*, 286(1), 71-77. <https://doi.org/10.1001/jama.286.1.71>



and underlying, leading individuals to consider their family's thoughts and opinions before making any decisions. Moreover, individuals believe that organ donation after their death would affect their family rather than themselves, granting them a sense of authority in the decision-making process. However, despite their stance on organ donation, many participants were reluctant to influence their family members' decisions, as they believed it **should be an intrinsically motivated choice**.

Individuals expressed a **strong preference for having direct conversations** with their family members to determine their stance on organ donation. Trusting these personal discussions more than pledges or information from social workers, a clear yes or no from family members translates to an acceptance or rejection to donate respectively. In the absence of such conversations, ambiguity arises, and individual perceptions and inclinations become influential.

Most organizations are prioritizing getting more pledges, overlooking the ineffective conversions of those pledges. Most pledgers fail to



engage in meaningful conversations with their families, and even those who do, **merely inform them without adequately preparing them.** Individuals need to discuss topics such as brain death, its appearance, whom to contact in case of donation, the donation process, addressing beliefs and dispelling myths to significantly increase the likelihood of a successful donation.

Some immediate actionable steps that can be taken to tackle the challenges at hand include:

- **Enhancing awareness campaigns:** Communicate that pledges are not legally binding. Emphasize the family's role in donation decisions and the need to have a conversation immediately.
- **Providing conversation guides and resources:** Offer conversation guides providing necessary information, movies or series that facilitate organ donation discussions, and dispel myths. These resources help potential donors initiate conversations and prepare the family in a comfortable and informed manner.
- **Healthcare facilities as a touchpoint:** Instead of limiting organ donation information to posters outside the ICU, distribute visual

infographics at touchpoints such as waiting areas and reception desks. This exposure stimulates conversations and increases awareness.

- **Tailoring messages to individual contexts:** There is no one-size-fits-all approach. Curate messaging to align with people's cultural, mental, emotional, and family contexts. Assure families that the donation process will be tailored to their circumstances, fostering comfort and ease.
- **Reimagine the pledge process:** Innovative ways to make it more interactive, effective, and engaging. This could involve incorporating technology, interactive elements, or alternative media to capture the commitment of potential donors.

While public campaigns have succeeded in raising general awareness, the next step should be to make organ donation a household conversation. Through these conversations, the gap between intention and action can be bridged, empowering families to honour the wishes of their loved ones and ultimately save more lives.



Editor's Note: The Family Donor Card, championed by the MOHAN Foundation, serves as a distinctive tool to advocate for organ donation in India and helps overcome the challenge of family conversation.



MOHAN
FOUNDATION



Gift Hope, Gift Life

www.mohanfoundation.org

Initiation of Organ Donation & Transplantation Program in Manipur

Pioneering Initiatives – A Glimpse



Shri. Sanjay Prakash

Managing Director & Chief Executive Officer, SBI Foundation

Project
Gift Hope, Gift Life

A B.Sc. (Honors) in Statistics from Patna University, he joined SBI in the year 1990. Over the last 33 years, he has served in various positions in the Bank, including operations and administration. In his present role at SBI Foundation, he gets to fulfil his passion for bringing about a change in the lives of the socially and economically weaker sections of the society, particularly improvement in their health conditions.

“Organ donation and transplantation are among the most remarkable medical success stories of this century. One individual has the power to save up to 8 lives. While India ranks among the top 3 countries for organ transplantation, there are still over 4 lakh people with organ failure awaiting transplants. SBI Foundation aspired to associate the brand of SBI with this major nationwide cause, strategically supporting it under CSR. To bring our intent into action, the project 'Gift Hope, Gift Life' was designed jointly with MOHAN Foundation to take up the challenge of improving the organ donation scenario in the country.

Over the last 5 years, we have been collaboratively working towards highlighting this issue and steering a paradigm shift. Under the program, we have set up a toll-free 24x7 SBIF-MOHAN Foundation Organ Donation Helpline in 8 languages. We are undertaking training and capacity building of healthcare personnel, and we have even started a support group for organ failure patients, transplant recipients and caregivers. We firmly believe that through public awareness campaigns, capacity development of healthcare professionals, and bereavement counselling in government hospitals, it is possible to positively change the state of mind of the people and significantly increase the country's organ donation rates. The efforts made by MOHAN Foundation in synergy with Government Hospitals across the country are integral in enhancing our reach in highlighting this issue and saving lives. We are committed to changing the current state of organ donation in India to enrich the lives of our future generations.”

SBIF – MOHAN Foundation Organ Donation Toll Free Helpline
1800-103-7100