

INDIAN TRANSPLANT

NEWSLETTER

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Guest Editorial

Can the Family of a Deceased Donor Direct its Organ Donation?

This article concerns itself with the dilemma faced by hospitals and organ distribution agencies when the family of a deceased donor asks for one of the retrieved organs to be allocated to a particular person known to them (not when the family seeks donation to a particular group of persons, a totally different issue, not looked into here). Two friends involved in this field – one named Pessimist (P) and the other, Optimist (O) – started discussing this issue.

P. First, this is illegal. There is no provision for such directed donation in our transplant law or any other law of our land.

O. No, this is completely legal, because the law of the land does not specifically prohibit it. All laws of the land are enacted to stop socially unacceptable practices, not to list all acceptable practices under the sun. Besides, no law maker can foresee all eventualities in a complex field. In this case, since the law does not prohibit such directed donation, concerned persons need to decide only on the basis of current acceptable medical and societal ethics.

P. But then, who owns a deceased person's organ? Can a family member say I own it and will give it to whoever I want to? Should it not be decided by a State authority?

O. Agree that no one has full ownership. In a few countries, a deceased person's organs generally belong to society (presumed consent). In most others, including India, the close relative has control over it, to say yes or no to organ retrieval. Only after they say Yes, the State authority can come into the picture.

P. What is the extent of this 'control'? Could the relative sell the organ to whoever pays the most?

O. No, it is conditional autonomy, on the same lines as living donation. There should be no commercial transaction in this, legally and ethically. Logic says that the close relative of a deceased person should be deemed to have the same control over the deceased person's organ as a living person has over his/her own organ – to donate it to a relative or a friend out of love, affection, empathy. The American Society of Transplantation says this clearly in its Position Statement:

A "directed donation" occurs when a donor family or a live donor directs the organ to a specific recipient. In most cases of live organ donation, the designated recipient is a family member, friend, or colleague. Thus, "directed" donation is the rule, rather than the exception, for live organ donation, as the emotional ties to the recipient are the basis for the donation. Directed donation is much less common for deceased donors, although it has occasionally led to successful organ transplantation in recipients designated by the deceased's family, based on family ties or friendships...The AST supports efforts to increase organ donation, including directed donations, based on principles of ethics, equality, fairness, and sound medical judgment. The circumstances surrounding a directed donation should be carefully assessed by the transplant team. Evidence of coercion, whether emotional, financial, or material, should lead the transplant team to refuse the donation."

Thus, the agency over one's own organ and the agency over a deceased relative's organ are to be viewed through the same prism.

P. If it is to be the same prism, why a State agency to distribute the organs? Why not leave it to the relative to decide who to give all the donated organs to?



Mr. C. E. Karunakaran
Managing Trustee
NNOS Foundation

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Novel family voucher scheme for living kidney donors

There are times, when a person might want to become a living kidney donor to help a younger family member with kidney disease, but by the time this family member actually needs the transplant the potential living kidney donor would be too old to donate. Jeffrey Veale at the University of California, Los Angeles, started a novel scheme in 2014 that would allow such kidney donors to donate to strangers and in return get a 'family voucher,' which could be later used by a named younger relative when they needed it. In 2019, the scheme was expanded to enable the donor to name up to five recipients for the voucher even if they did not have kidney disease. This was to target people who wanted to be altruistic kidney donors to strangers but were apprehensive that a family member might later require a kidney transplant. The voucher was an "inheritance" that the family could utilise if needed in the future. A recent review of the first 250 living kidney donors who requested family vouchers has enabled kidney exchanges resulting in 573 transplants. It was also found that the waiting time for the kidney transplant was one to five months for the six people who have used their voucher. This is in contrast to a waiting time of several years for a deceased donor kidney transplant.

A transplanted kidney that is 101 years old!

Daniel Lane is 74 years old and his transplanted kidney is 101 years old! Mr. Lane who lives in Montrose, Colorado, USA had his kidney transplant surgery on 10th May 1971. He was 24 at the time and his mother Evelyn Lane who was the donor was 50. Mr. Lane had a congenital defect that led to kidney disease and, following a bout of influenza, he ended up with kidney failure. His kidney transplant was performed in Denver by a team led by Dr. Thomas E. Starzl, who has often been called the 'father of modern transplantation.' Mr. Lane's mother died in 2014.

Japan performs world's first lung transplant from living donors for COVID-19 patient

In April 2021, doctors from Kyoto University Hospital, Japan performed the world's first lung transplant from living donors for a patient who had severe lung damage due to COVID-19. The patient was a woman from Kansai, in the western region of Japan. Her husband donated a part of his left lung and her son donated a part of his right lung. The surgery that took 11 hours was performed by a 30-member team headed by Dr. Hiroshi Date. He said that they had demonstrated that there was hope for such patients requiring a lung transplant through living donors, not only deceased donors.

Spain maintains world's highest organ donation rate

Spain has been a global leader in organ donation and transplant for almost three decades. The country's healthcare system seems to be still performing better than other countries despite the health crisis caused by the COVID-19 pandemic. In 2020, the organ donation rate in Spain was 37 per million population (pmp) which is comprehensively higher than in other countries, even pre-pandemic. For instance, in 2019, Germany had 11 donors pmp, Australia 22, Italy 25, and France less than 30.

Last year, about 4,425 organ transplants were carried out in Spain with organs donated by 1,777 people. Apart from that, 268 people made live donations of a kidney or a portion of their liver. In 2022, the country aims to achieve 50 donors pmp and this strategic plan of the Spanish National Transplant Organisation (Organización Nacional de Trasplantes or ONT) is called "50X22."

The Director-General of ONT, Beatriz Dominguez-Gil highlighted in a speech that the system has made organ procurement a routine activity regardless of the circumstances of death, and that is the reason behind their success.

Tawakkalna launches service to register for organ donation in Saudi Arabia

In an effort to promote altruistic organ donations in Saudi Arabia, Tawakkalna has officially launched an online registration service for the organ donation programme, making it easier for the public to register on the national database.

The Saudi Data and Artificial Intelligence Authority (SDAIA), launching the registration service for organ donation on its health portal, stressed that this was one of the services it was offering to help realise the aspirations of wise leadership and its directives on the importance of supporting the noble act of organ donation. The Saudi Center for Organ Transplantation (SCOT) seeks to register the civilians who are willing to donate their organs upon their death.

Tawakkalna system and application focuses on facilitating the organ donation process, whether through the SCOT or Tawakkalna website or through the Tawakkalna application on smartphones and those who register as donors will be automatically added to the database. This new registration service will be gradually expanded to include all related services.

MOHAN Foundation to participate in Congress of the Asian Society of Transplantation (CAST) 2021, Malaysia

Dr. Sumana Navin, Course Director and Ms. Sujatha Suriyamoorthi, Manager-Information Systems, MOHAN Foundation have been invited as speakers at the prestigious 17th Congress of the Asian Society of Transplantation, Malaysia that will be held from 25-28 July 2021. CAST is the premier biannual scientific event in Asia which specifically focuses on various aspects of transplantation. They will deliver the following lectures:

- ◆ **Challenges in family donor conversations** (Pre-Congress Workshop: Organ Donation & Procurement) – Dr. Sumana Navin and Ms. Sujatha Suriyamoorthi
- ◆ **Burnout amongst donor coordinators: is it real?** (State of the Art Symposium) – Dr. Sumana Navin



Parliamentary Standing Committee recommends continuation of National Organ Transplant Programme

The Parliamentary Standing Committee on Health and Family Welfare, headed by Prof. Ram Gopal Yadav, recommended the continuation of the National Organ Transplant programme (NOTP) for the period 2021-26 with a budget allocation of Rs. 426.61 crore. In its report, the committee said that the total number of transplants done in the country increased from 4990 in 2013 to 12666 in 2019 indicating a marked improvement in infrastructure for undertaking transplants. Also, 529 hospitals undertaking transplantation or retrieval out of the total estimated 690 in the country were now registered with the National Organ and Tissue Transplant Organisation (NOTTO), New Delhi for the purpose of networking and National Registry.

The central government implemented the NOTP to promote organ donation and transplantation through the establishment of NOTTO, five Regional Organ and Tissue Transplant Organisations (ROTOs) and State Organ and Tissue Transplant Organisations (SOTTO) as per the Transplantation of Human Organs and Tissues Act, 1994 that was amended in 2011. SOTTOs have now been established in 12 States. At present, only 16 states and Union Territories have adopted the Amendment, 2011 and Rules, 2014. The Committee has recommended that all State Governments adopt the amended legal framework and that the Health Department should seek proposals from State Governments for the establishment of SOTTOs and ensure that funds are optimally utilised for the purpose.

'Last act' – Kannada actor Sanchari Vijay saves lives through organ donation

National award-winning Kannada actor Sanchari Vijay's 'last act' will be forever remembered. His family took the humane decision of donating his organs after his untimely death. The 37-year-old actor met with a bike accident on 12th June this year in Bengaluru. His bike hit an electric pole and he sustained grievous head injuries that resulted in brain death. His brother Siddesh Kumar said that the family decided to donate his organs and offer organ failure patients hope of a new life. Vijay won the National award for his performance in the film, Naanu Avanalla...Avalu (I am not a he, I am a she) about a transwoman having the right to live life on her terms and that humanity comes first. Vijay's act of organ donation exemplified just that.

Rising number of deceased organ donations in Mumbai

Mumbai city witnessed a boost to organ donation and transplantation amidst the COVID pandemic situation. The city recorded two deceased organ donations within 24 hours, with seven patients benefitting from a life-saving transplant after families agreed to donate their deceased loved ones' organs at Jaslok Hospital, Pedder Road and MGM Hospital, Vashi. This follows four donations in a 44 hour-period between 3rd and 4th March 2021, taking the tally to 11 donations till mid-March 2021. There were 30 donations in 2020 and 79 in 2019, reported Zonal Transplant Coordination Centre (ZTCC), Mumbai (www.ztccmumbai.org).

Online pledging for organ donation using QR code initiated by ZTCC, Pune

The Zonal Transplant Coordination Centre (ZTCC), Pune became the first of the four ZTCCs in Maharashtra to initiate online pledging for organ donation using a QR code. Mrs. Arati Gokhale, central coordinator, ZTCC, Pune said, "Once you scan the QR code, it directly takes you to the website (ztccpune.org) where Form number 7 (organ and tissue pledging) is. As soon as you fill in the details, there is an auto reply and the donor card is emailed to you." This data is then sent to the National Organ and Tissue Transplant Organisation (NOTTO), Government of India.

Doctors find new hope for patients with diabetes

The first simultaneous pancreas-kidney (SPK) transplant surgery on a patient with type 2 diabetes was successfully conducted for the first time at the Post Graduate Institute of Medical Education and Research (PGIMER) in Chandigarh. The patient was a 54-year-old man from Roorkee who was suffering from diabetes for over a decade and was on dialysis because of kidney failure. While SPK transplant was recommended in type 1 diabetics with kidney failure, it was not recommended in type 2 diabetics with kidney failure. The thinking was that the pancreas transplant would not be useful due to the presence of insulin resistance in patients with type 2 diabetes. However, this has changed in the last few years. PGIMER has successfully performed 25 SPK transplants in patients with type 1 diabetes. This transplant for type 2 diabetes has given new hope to many patients.

Second heart transplant at KLES Hospital, Belagavi

In a press conference that was held in March 2021, doctors at KLES Dr Prabhakar Kore Hospital in Belagavi, Karnataka spoke about the second successful heart transplant that was performed there on 26th February 2021. The first heart transplant was performed in February 2018. This time around a 17-year-old boy got a second life through a 52-year-old brain dead man whose heart he received. The boy was operated on by Chief Cardiac Surgeon, Dr. Richard Saldanha and his team. Dr. Saldanha told the media that the boy was diagnosed with 'dilated cardiomyopathy' (a condition where the heart muscles weaken and stop pumping blood) and he was advised to register in Jeevasarthakathe, the Government of Karnataka transplant authority's heart transplant waitlist.

The matching heart was procured from Kolhapur as the brain-dead donor's relatives agreed to altruistically donate their beloved one's heart after counselling by Dr. Veeresh Manvi, Dr. Kothiwale and their team. The seven-hour surgery was performed by Dr. Saldanha, Dr. Mohan Gan, Dr. Kiran Kurkure, Dr. Ravi Ghatnatti, and Dr. Praveen Tambrallimath. The boy's recovery was good. The transplanted heart was functioning normally and there was no evidence of infection or rejection.





Dr. Suryakumari Duggirala
 Founder – President, The ALPS
 The Academy of Life and People Skills



Dr. Suryakumari with Dr. Sunil Shroff, MOHAN Foundation team and Transplant Coordinators' Training Programme participants

Who would have thought that a quiet young girl in school would one day become a successful Life Skills Coach and 'Edupreneur' – meet Dr. Suryakumari Duggirala, President and Founder of The Academy for Life and People Skills (The ALPS).

Over the decade that I have known Dr. Suryakumari, almost every interaction that I have had with her has had a Eureka moment! Whether she is speaking in the classroom or having a regular conversation there is 'the discovery of something new' for the audience to which she laughingly remarks, I simply tap the right buttons in you!

Dr. Suryakumari (Dr. Surya as she is called) has been on the faculty of MOHAN Foundation's Transplant Coordinators' Training Programme since 2011. This was in the early years of the launch of this unique structured course for transplant coordinators in India and South Asia. She started off with sessions on Human Resource-Organisational Behaviour (HR-OB) and Soft Skills that were filled with practical learning. She has covered myriad topics based on the training requirement: Few standalone ones are: 'Bringing about Social Change using the Tools of Social Media – Organ Donation' and 'Health Care Professionals and Health Care Managers – Effective Communication Skills.' Given the teaching challenges that the COVID-19 pandemic brought, she quickly adapted herself to the virtual world and made her sessions on 'Communication Skills in Healthcare Management' and 'Conflict Resolution' interactive with activities and group discussions. Excerpts from an interview with her:

Dr. Sumana: How do you think 'Stress Management' is important, especially for healthcare professionals?

Dr. Surya: Let me begin by saying that just as 'pride' can be a positive and negative emotion, the word 'stress' by itself can mean either. In Physics, it refers to the interaction between a force and the resistance to counter that force. It is a non-specific response of the body to any demand. Hence stress is as normal as a reflex action and the body gets back to normal mode after the stressful situation is over. How is it over? With your problem solving skills, coping skills and resilience. Most stress consists of an adrenaline rush and a euphoria of having achieved or overcome, I call it, a situation rather than a crisis. What is generally referred to as Eustress, like before an exam or a presentation. The stress that pushes you to perform well. Positive.

Stress is a given, whereas 'Stress Management' is a misnomer. I believe you can 'manage' yourself to handle stress than 'manage stress.' Hence our

self-designed flagship programme, 'Stress Proof Yourself.' Here we coach participants and equip them with skills to overcome adverse situations that are part of growing up and life. Yes, we all panic, get agitated or angry under various circumstances. That is momentary reaction, aka reflex action. What follows is how you manage the situation under stressful circumstances by working towards a solution for that. It does not mean that one becomes devoid of emotions like grief and sadness but you are better equipped to handle stressful moments that are part of life. This way you remain in control of the situation and emerge a winner for a lifetime. You become a more confident and stronger person.

Dr. Sumana: You have been with MOHAN Foundation for a decade. What are your takeaways?

Dr. Surya: I am like many people out there who want to do a few good things in life apart from the 'roti-kapda-makaan' (food-clothes-house) but do not know how to go about it. I am humbled by the opportunity to work with the Foundation. Yes, in true Surya style as you always say, I am sincere in whatever I do. I have always looked up to Dr. Sunil Shroff, Managing Trustee, MOHAN Foundation for his simplicity and ever-smiling countenance while doing such voluminous work. Thanks to the genuine and honest work that you and your cheerful team do, I have pledged my organs and go about creating awareness however I can. For this, I need to equip myself with the tools. Hence when you asked me to vet the One-day 'Gift of Life' online course, it was an opportunity for me to upskill myself to provide you with the right feedback as a student.

"I started the one-day 'Gift of Life' online course with a lot of excitement and eagerness. It has been an enriching and a learning experience. The course has been curated with in-depth and meaningful content. The lessons flow well into each subsequent topic, give a lot of information that add tremendous credibility. From a non-medico perspective, it was understandable and simply laid out. What is outstanding is the transparent yet dignified way in which a delicate and sensitive subject like organ donation has been handled without being overtly pleading. The facts were laid out effectively and a case presented, leaving the readers to take a decision on their own (e.g. ethics topic discussion on preference of kidney donation between live donor and deceased donor). This can be introduced in all forums – schools, colleges, work places and social media platforms for better reach and penetration. This will also help dispel any distrust amongst the public. There are several online educational websites now like Coursera, Upgrad etc. MOHAN Foundation can collaborate with these to include this as a free course." – Dr. Suryakumari

Impact of COVID-19 Pandemic on Transplantation – Evolution of patient care



Dr. Shruti Tapiawala

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The world was starting to wake up to the COVID-19 viral pandemic in March 2020. A time when the World Health Organisation, Centre of Disease Control were trying to study the virus, its mechanisms of spread, its pathogenic effect and more importantly a way to treat it and prevent it. The world was experiencing the horrifying effects of the virus which was overwhelming the hospitals and cemeteries all around the world. Even the most developed nations found themselves unprepared to handle the sheer number of people who were getting infected, requiring hospitalisations and critical care. The virus was proving itself more than a flu.

India fared no differently. India saw one of the earliest and strictest lockdowns to control the spread. Today I will share our journey with our patients through the pandemic. Early March 2020, we started making protocols and educating our dialysis staff and hospital staff to screen patients in terms of symptoms, travel history or contact with an infected person. We could see the fear in their eyes as well as patients' eyes. PPEs were deployed for all staff- we could see the staff trying to live with it. We could even see the paramedical staff being not allowed in their own apartments and families asking their near and dear ones to leave the job in wake of the pandemic putting them at risk at their work places. We were getting phone calls from our society managements whether we were working in COVID set-ups, as if wanting to indirectly understand if we were a threat to them. One would dread that we would also be told not to come back home.

Dr. Sumana: You seem to have internalized this learning, right?

Dr. Surya: Oh really, I did not look at it that way. Perfection has become obsolete, it's all about professional excellence now! Although I am Faculty for Communication Skills, Soft Skills and HR-OB, I have constantly educated myself as much as I can about the organ donation cause. In management we call it 'Product Knowledge' (she laughs)...whatever you sell or talk about it, as in marketing or customer care, you need to know about it first! Oh yes, I stretch it a bit perhaps and take everyone along so much that family gatherings too have had an Awareness Talk!

Dr. Sumana: You were invited by the Healthcare Sector Skill Council to be on the Expert Committee that was formulating National Occupational Standards for a Transplant Coordinator. How was that experience?

Dr. Surya: It was an honour and privilege I cherish. To be nominated as the only Life Skills Coach amongst eminent doctors and social workers of the country, I am humbled and fulfilled that I have held the torch given to me responsibly.

Dr. Sumana: Can you tell us about your recent ranking in the corporate world?

Dr. Surya: As one among the Top 10 Women Corporate Trainers 2021 in the country? Women Entrepreneur India conducted a survey of 210 Women Corporate Trainers and interviewed me. That was a full-on thrilling moment, I must admit when CEO Insights magazine featured the results. I owe it to all my clients, participants and a lot of it to my pro bono work.

Dr. Sumana: What is your mantra?

Dr. Surya: "Don't be intimidated by what you don't know. The ability to learn is the most important quality a leader can have." I am driven by a quest to learn and this is what I impart to my participants and students as well. My life lessons have come from my parents who lived the values and never ever preached.

Dr. Sumana: You recently started a unique webinar series called The ALPS Conversations, "Quiet achievers – Women at work." What is it about?

Dr. Surya: I believe that success and happiness is not like 2-minute Maggie noodles, an instant comfort food. It has to be earned with a lot of hard work and dedication. That's what we are told, boys and girls in the growing years. But for the average woman in the patriarchal world we live in, it comes through a number of 're-start' buttons. I wanted to showcase and celebrate women achievers who go about rebuilding their careers amidst the changes brought about by marriage and children. How difficult was the journey and how most, or shall I say all of us carry on while the world is QUIET. The whole world knows the celebrities but one may not be aware of how the women in one's own family have succeeded. You can see them all on YouTube. We were eight women, but actually the number is 'all women', I can safely say! Through my interactions with this eclectic group, you can see the importance of self-belief, self-love, courage, humility, respect for others and hard work for success that made for illuminating conversations.

Dr. Sumana: You have varied interests, how do you manage to address each?

Dr. Surya: I guess by keeping my interests alive! As a student, I enjoyed Economics, Psychology and English. I was in a dilemma as to in which I should specialise. By keeping my vision in perspective, I seem to have achieved all my goals to a reasonable extent. A doctorate in Economics and all other supplementary studies in English and Psychology I derived by learning on the job as each opportunity came up. Teaching is what I love, although sadly there is scant respect for both the noble professions in our country, I continue to dedicate myself by reskilling and upskilling myself.

– Dr. Sumana Navin

Let me start with the story of patients on dialysis. A shocking situation awaited us in March 2020, when hospitals were told to stop inpatient and outpatient services due to 90 per cent staff getting infected and patients started calling us that they did not have a place for dialysis as their units had shut down and would we be able to accommodate them. We were witnessing deaths due to patients not getting dialysis for weeks together as they were denied dialysis at their own centres. Another group was the patients who tested positive and were treated as a stigma. They were told not to come for dialysis at their parent units as they could not dialyse COVID patients. These patients did not receive dialysis as they did not know what to do and would either succumb to complications related to not receiving dialysis or require ICU admission for the same. As nephrologists we are a cohesive group in Mumbai. Few members of the Mumbai Nephrology group namely Dr. Vishwanath Billa and Shrirang Bichualong with IIT Mumbai came up with Project Victory – a software which would help centralise the dialysis bed allocation and ensure dialysis availability to one and all. This was an online portal which would help a patient get a dialysis bed within 24 hours of being added online with a positive status. All hospitals could nominate an administrator (nephrologist) who was in charge of updating the number of COVID dialysis beds available at their centre to accept / accommodate a patient and add their own patients and request dialysis slots if required. This way by April 2020 we were on track and our dialysis patients could be taken care of. It was indeed a feeling of fulfilment to be able to work as a BIG team – **everyone working with everyone for every patient!**

In May 2020 we were fairly confident regarding the quarantine periods, eligibility for hospital admission, treatment (at least we were learning how to diagnose, grade the severity and treat with whatever evidence was available- although feeble and changing by the day). In May 2020, when we had come around handling ourselves, our families and our patients with the COVID pandemic, we realised that there were so many patients whose transplants were held back due to the fear of contracting the virus in a post-transplant situation and these patients were actually being exposed to contracting the infection as they had to come to their dialysis units every other day. We were now attending and participating in virtual webinars where we could discuss and exchange notes nationally and internationally. We realised we could safely plan to take transplants through and this will actually help patients stay healthier as it would help them get transplanted which was a healthier option for end-stage kidney disease and it would help them stay at home and avoid being exposed to getting COVID infection. The hospital outpatient departments were slowly starting in a hybrid manner – partial virtual consultations and few physical appointments were initiated. Next hurdle in restarting the transplant programme was that the patients were very scared and they were refusing living or deceased donor transplants. Deceased donor organs were being refused by patients and precious organs were being wasted. Patients who had living donors were getting unwell as time passed by making them unfit despite having living donors in the family.

Our team believes in educating the masses and shedding the ignorance which will show patients the path to health. It has been our tradition for decades (since early 1990s) to do a weekly education programme for our patients. It would help patients meet their peers, learn about their disease and coping strategies. Our weekly education activity had stopped since March 2020 due to the restrictions of the pandemic and the need to avoid a gathering of people, let alone patients. We decided to restart education. We started our weekly education sessions online. Initially patients found it difficult as not everyone was technologically comfortable. We had our coordinators handhold them through the technological issues and slowly the numbers of attending patients and their family members picked up. We could reach out and discuss COVID prevention, care on dialysis, chronic

kidney disease care and the ease of transplant and safety. We could help patients far and wide, thanks to technology. The transplant programme which had been at a standstill from March 2020 picked up from June. In August our institute was offered limbs from a deceased donor. We bravely went ahead with the transplant. The young girl today has functional upper limbs!

Second wave started in March 2021 after 2-3 months of respite. This time the virus was different and we realised that the strategies to treat patients had to change. This time the lung damage was severe and people also had clotting abnormalities leading to cardiac and cerebral events. Vaccinations were ongoing but this time the country was looking at a severe lack of facilities including oxygen supplies, intensive care beds for COVID infected patients. In many communities, an informal network of providers including rural medical practitioners, frontline health workers, non-governmental organisations, and community self-help groups came together to meet with the chronic care needs of the people, including arranging medications and teleconsultations. We were seeing much younger patients and mortality was high despite best of the services. There were horrifying reports from other cities and states in the country where people were dying as they did not get oxygen, bodies had no place to be buried or cremated. In Mumbai we did not see lack of facilities as we were a first-tier city of India with reasonably good health care network. In Mumbai the Project Victory was revived to allocate patients if required, but the crisis was not as much as we saw last year, as we now had a system which was already in place.

This time, unlike last year, we lost many of our patients (chronic kidney disease, dialysis and transplant) to the COVID-19 infection, some with all the care and some who could not get facilities being in smaller cities. As a country we rose again and with strict guidelines, preventive measures and aggressive vaccination drives the wave is somewhat controlled and there has been a sharp drop in the cases.

My take home message to all

As we cross everyday, our only weapon remains prevention strategies and education of the masses to mask up, maintain distance and ensure that we encourage people to vaccinate themselves and their acquaintances.

The human race shall overcome all the adversities and prove themselves to be a superior being.

Take care and be safe – make others safe!

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
Date: 30 June 2021



Signature of Publisher

Anudaan – Making Transplants Affordable

MOHAN Foundation is happy to announce its new endeavour, 'Anudaan – Making Transplants Affordable' for providing help to the economically poor and needy patients so that they can also have access to life-saving organ donation and transplantation.

Organ transplant costs are exorbitant and a huge number of organ failure patients are not benefiting from this life-saving procedure advancement in medicine as they are ill-equipped to bear the financial burden of the transplant and subsequent follow-ups. Anudaan aims to support such economically disadvantaged patients by joining hands with philanthropic individuals, corporates and other NGOs and by helping such patients raise funds through crowdfunding.

There are very few public hospitals performing transplants. More than 95% of organ transplants especially of organs like livers and hearts are currently performed in the private sector where costs range from Rs. 20 to 25 lakhs. Even relatively less complex kidney transplants cost between Rs. 8 to 10 lakhs. More State Governments need to pave the way for making transplants affordable and help patients with post-transplant medication support. Till then, NGOs and such entities need to come forward to bridge the gap.

Any requests for financial help under 'Anudaan' are accepted only from the hospital authorities. Patients with annual household income of less than or equal to Rs. 5 lakhs are considered as eligible for help. The hospital is expected to offer support to the poor patient via a subsidized transplant cost, possibly under their CSR. This gives a lot of comfort to the Anudaan Committee as the Hospital themselves are demonstrating their commitment to helping poor patients. Finally, the Anudaan Committee also reviews funds raised/committed by self/family/friends or through other Trusts/Foundations, to look at the gap and thereafter commit its support.

Since its launch in January 2021, Anudaan has supported 3 young, bright girls with their transplants.

अनुदाान
Making Transplants Affordable

An initiative touching lives...

ASPIRES TO BE A LIVER TRANSPLANT SURGEON
AARADHYA AKUNURI
6 yrs, Telangana
Liver Transplant on Jan 16, 2021

ASPIRES TO BE A TEACHER
MS. J. SUSMITHA
27 yrs, Telangana
Kidney Transplant on Apr 1, 2021

ASPIRES TO BE A FASHION DESIGNER
MISS SUJATHA CHOUGULE
21 yrs, Goa
Liver Transplant on Apr 19, 2021

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

A MOHAN FOUNDATION project

– Preeti Goswami
Programme Officer (Delhi-NCR)
MOHAN Foundation



Aaradhya with her Doctor

Miss Aaradhya Akunuri, 6 years, Sirsapalli Village, Huzurabad, Telangana
Underwent Liver Transplant on Jan 16, 2021 at Global Hospital, Hyderabad
Anudaan contributed 8.5 lakhs raised with the help of philanthropic individuals

"I thank everyone who worked round the clock to bring back smiles to our family. We will always be grateful to MOHAN Foundation, MFJCF and Transplants – Help the poor Foundation".

Winner Akunuri, Father of Aaradhya Kumari



Susmitha with her son

Mrs. J. Susmitha, 27 years, Village Agapet, Telangana
Underwent Kidney Transplant on Apr 1, 2021 at Kamineni Hospital, Hyderabad
Anudaan contributed 2 lakhs & worked with the hospital to bring down the transplant cost

"I am very happy now. With support from MOHAN Foundation, the transplant went very smoothly without any fear. MOHAN Foundation is truly God's gift to us. I now feel confident about returning to a full-time job."

Somani Jatothu, Susmitha's Husband



Sujatha with her mother and sisters

Miss Sujatha Chougule, 21 years, Goa
Underwent Liver Transplant on Apr 19, 2021 at Aster CMI Hospital, Bengaluru
Anudaan contributed 2.5 lakhs

"I would like to thank MOHAN Foundation as they have done a very good job. Without them, my sister's liver transplant was not possible. They have given her a new life."

Sanika Chougule,
Sister of Sujatha Chougule

Simple Living, High Thinking

On 6th April 2021, MOHAN Foundation received a call from Dr. Kuldeep (Consultant, Medical-ICU at the Artemis Hospital) informing us about a family who wished to opt for body donation. I immediately went to meet him and the family, subsequent to which we coordinated with Dadhichi Deh Daan Samiti (an NGO that helps facilitate body donation on behalf of families) and the body was handed over to AIIMS (All India Institute of Medical Sciences) New Delhi.

The deceased noble soul was 72-year-old Mrs. Prabha Singh.

Mrs. Prabha Singh was born and brought up in Ghaziabad and she had a Master's degree in Hindi. She got married to Mr. Shripal Singh and post marriage she shifted to Chhattisgarh where her husband was working with BALCO (Bharat Aluminium Company). She started working as a teacher in DAV school in Chhattisgarh and by the time of retirement she was the principal of that school. Her husband retired in 2000 and after 27 years of living there, they moved back to Ghaziabad.

Prabha and her husband had recently completed 50 years of married life and shared a very close bond. While they had their share of disagreement, they were very deeply aligned in their thinking, their values and way of life. The couple had taken the decision to donate their bodies after death for medical research. They had taken this decision independently, without discussing with anyone and wanted their children to honour their wish.

Her son, Swadeep, while speaking with me told me that donating her body was not an option for them. The couple had discussed this just 6-7 years back and his father reminded them of this discussion when the news of her death was declared by the doctor. It was her wish and it had to be honoured.

Swadeep himself had faced a tragedy when in 2016, he lost his wife. It was during this tough time that his parents shifted with him to Rajasthan to take care of their two grandchildren. Swadeep says, *"She was a very emotional and kind hearted woman who believed in **simple living, high thinking**. She was a teacher, a great administrator, a homemaker and after retirement decided to completely devote her time to family."*

He further adds, his mom was the *"backbone of the family – how she took care of my kids is commendable. More than a grandmother she was a mother to them."*

She was an animal lover and especially very fond of cats and they had two cats at home. Recently Swadeep had bought a new car and he took his mom for a drive. *"She was very emotional during the drive"*, reminisces her son.

During these unprecedented times the family has shown courage to fulfill the last wish of their beloved one and MOHAN Foundation salutes them for this noble act. It also reiterates the importance of family discussion on donation.

Shafia Malik
Transplant coordinator
Artemis Hospital
Gurgaon

Editorial...continued from page 1

O. You sound very logical. The reality is that only in extremely few cases that the family of a deceased person finds that a relative or a friend needs an organ at that particular time. Experience shows this.

P. Okay, let us stick to logic. You agree with me that law does not specifically allow this, but since it does not specifically disallow it, you will use logic to decide. Does not logic tell you that all organ donations must be altruistic? Is such directed donation altruistic?

O. It is largely altruistic, because three to five organs generally get donated from a deceased person. And very rarely, the relatives find that one of them is needed by a person known to them and so direct that organ; hence the organ will go to that directed person and not to the one on the top of the waitlist of the State agency that distributes organs. Even there, it gets donated to a relative or friend out of empathy, the same as in living donation. The other organs get allotted to the State waitlist per normal procedure. This may not fit your definition of 100% altruism, but even so, such a donation has to be accepted as it saves the life of a person, even if not the most deserving one, per accepted criteria (like all living donations) and a few more fully deserving persons who may take the other organs. Most in the world consider this as the key factor in deciding on this issue. Avoid "wasting potentially life-saving resources" is a common refrain. The American Medical Association in its Code of Medical Ethics puts it succinctly: "Directed donation policies that produce a net gain of organs for transplantation and do not unreasonably disadvantage other transplant candidates are ethically acceptable."

P. Even if I agree that this kind of direction for one organ is also mostly altruistic, I have one concern. If I start allowing this in my State, will it not open a Pandora's box with people pretending it to be altruistic, but really selling that organ surreptitiously, as happens often in living donation? Besides, if I am a decision maker in this area, why should I take a needless risk of possibly getting investigated later?

O. Sounds logical. Experience so far shows that it is extremely rare for such directed donations to happen in Tamil Nadu (TN), where it is officially allowed (through Guidelines established by the Advisory Committee) and in other countries too where it is allowed. And there is no hint of any wrong doing anywhere. Among the around 3000 deceased donor organs transplanted in TN over eight years, the number of such cases were in single digits. There have been a few more cases too in other States like Gujarat and Maharashtra. 'Just one or two such cases in a couple of years' in the UK.

As for risk taking, all decisions in the transplant field carry some risk. In TN, there is a requirement that the donor hospital head has to declare that he has looked into the issue and is convinced that the directed donation sought is genuine. It will be unethical to deny lifesaving opportunity to three or four persons just to keep ourselves comfortable.

P. Your last point seems valid. However, should we not be establishing some Rules such as restricting such donations to near relatives and to those that have been in the waitlist for quite sometime?

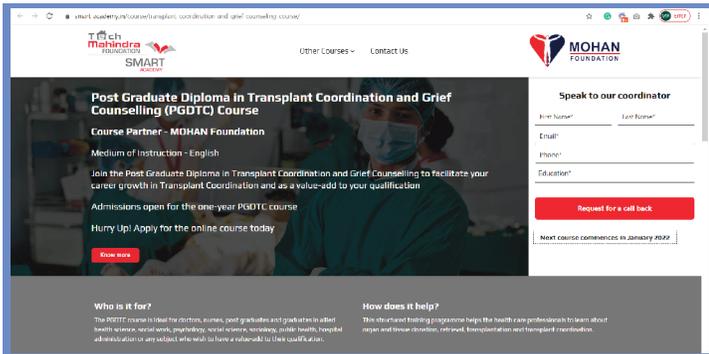
O. My view is to avoid all kinds of restrictions and leave it to the discretion of the organ distribution agency to take a call in each case. It can be to anybody, so long as it is a genuine direction. Other countries go out of the way to help the donor family when they feel a need to help a friend or relative. If the organ is not found to be suitable to the directed person, swap donation with another living donor is arranged to help both sides, or the directed person is given priority in organ allocation in future. I strongly recommend such outgoing help to the donor family. Ultimately, it is such empathetic approach and flexibility given for decision making at the ground level that will promote organ donation (as experienced in TN) as against any over centralised approach and bureaucratic reading of the letter of the law.

P. Thank you for convincing me that scarce lifesaving resources should not be wasted and that the feelings of the altruistic donor family has to be respected, need to be the key factors to inform our approach to this issue. I am considering changing my name to yours.

O. Hi, Welcome, Optimist.

The two Optimists then shook hands and went their ways.

Tech Mahindra Foundation SMART Academy Launches MOHAN Foundation's Online Courses



MOHAN Foundation's One-year PGDTC Course displayed on the SMART Academy Website

MOHAN Foundation has collaborated with Tech Mahindra Foundation SMART Academy to support the cause of organ donation and transplantation with an aim to train youth in transplant coordination for saving lives. MOHAN Foundation's three online courses – 'Gift of Life' – one-day Certificate Course on Organ Donation, one-month Transplant Coordination Professional Certificate (TCPC), one-year Post Graduate Diploma in Transplant Coordination and Grief Counselling (PGDTC) are now linked to the SMART Academy portal. MOHAN Foundation and Tech Mahindra Foundation SMART Academy announced this partnership on all their social media platforms.

Feedback

"Frankly, I was not sure how the "Transplant Coordination Professional Certificate" one-month online course would be helpful. Now on completion of the course, I would like to emphasise that this broad-based course is eminently helpful for everyone associated with organ and tissue retrieval and or transplantation. The curriculum covers almost all aspects of organ and tissue donation, retrieval, preservation, transportation, basics of transplantation procedures, rules & regulations governing live and deceased organ & tissue donation and transplantation, grief counselling, relevant social, religious, ethical and humanitarian issues.



Dr. Arup Kumar Mandal, M.Ch (Urology)
Professor, Department of Urology, All India Institute of Medical Sciences, Rishikesh, India.
Formerly Professor & Chairman, Department of Urology, PGIMER, Chandigarh

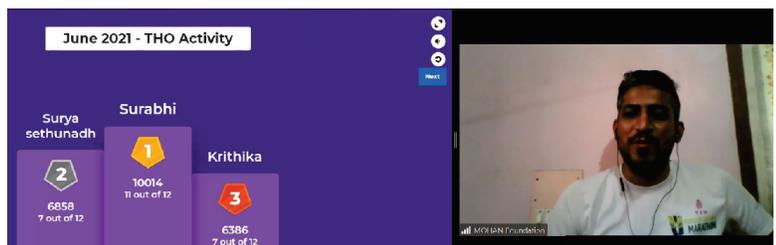
Free and easy access to call and interact with the course coordinators, provision of printed course material and learning through case-based studies made this training complete in all aspects. Not only does it make one empowered to work as an empathetic transplant coordinator, it improves one's understanding on the concept of Human organ transplantation and acts as a social worker, motivator, educator and improves public awareness. The faculty who conducted/coordinated the course are knowledgeable, able communicators, open minded and always eager to help. Free and unlimited access to course material during the duration of the course helps to learn at one's own pace. I consider myself empowered on successfully completing the Transplant Coordination Professional Certificate course with MOHAN Foundation."

Transplant Coordination Professional Certificate online course successfully conducted for March, April & June 2021

The online one-month course 'Transplant Coordination Professional Certificate' was successfully conducted in March, April and June 2021 respectively. The participants came from various parts of India such as Pondicherry, Telangana, Kerala, Uttar Pradesh, Tamil Nadu, Uttarakhand, West Bengal, Maharashtra, Karnataka, Himachal Pradesh, Bihar, Uttar Pradesh, Jammu & Kashmir, Haryana, Bihar, Delhi, Assam, Punjab, Chhattisgarh, Andhra Pradesh, Madhya Pradesh, Gujarat and Odisha. The training also had an international representative from Dhaka, Bangladesh. There were interactive webinars held as part of the training. A total of 83 participants in these three batches completed the course and received their certificates.



Mr. Gipson John talking about the roles of recipient transplant coordinator



Mr. T. S. Siva Shankar congratulating the top scorers of the quiz on the Transplantation of Human Organs Act



Ms. Rathi R explaining the role of a donor coordinator



Ms. Sohini Chattopadhyay sharing her views on 'Why majority of living organ donors in India are women'



Synchrony Dialogues – A Motivational Talk by Dr. Venkat Sumantran



Dr. Venkat Sumantran speaking about kidney transplants in India

On March 6, 2021, MOHAN Foundation in association with Tamilnad Kidney Research Foundation (TANKER), International Federation of Kidney Foundations – World Kidney Alliance (IFKF-WKA) and Transplant Recipients of India & Organ failure patients – A Movement to Provide Hope (TRIOMPH) organised a webinar to mark World Kidney Day which was titled, 'A motivational talk by Dr. Venkat Sumantran.' Dr. Sumantran is a business leader, technocrat, academic and author with over 30 years of experience in mobility across the US, Europe and Asia. He is an advisor to several Fortune-100 organisations and has spoken in multiple national and international forums. He is also a kidney donor himself.

Synchrony Dialogues – Lung Transplants Post COVID-19 & Other Options



Panelists – (from left) Dr. Unmil Shah, Ms. Pallavi Kumar, Mr. Ravi Dasari (lung transplant recipient), Dr. Kumud Dhital, Mr. Pranav Munjal (lung transplant recipient), Dr. Sandeep Attawar

On June 12, 2021, MOHAN Foundation in association with Transplant Recipients of India & Organ failure patients – a Movement to Provide Hope (TRIOMPH) and the Network & Alliance of Transplant Coordinators (NATCO) organised a webinar on 'Lung Transplants Post COVID-19 & Other Options.' It was supported by SBI Card and SBI Foundation. The webinar was moderated by Dr. Sandeep Attawar (Heart & Lung Transplant Surgeon & HOD, KIMS Hyderabad). Dr. Kumud Dhital (Cardiothoracic & Transplant Surgeon, Chairman-Heart & Lung Committee, The Transplantation Society) and Dr. Unmil Shah (Transplant Pulmonologist, Institute of Heart & Lung Transplant, KIMS Secunderabad, Telangana, Gleneagles Global Hospital, Mumbai) were the experts. Two lung recipients, Mr. Ravindra Babu Dasari and Mr. Pranav Munjal, shared their experiences with the audience.

Synchrony Dialogues – Planned Parenthood Post Transplant



Panelists – (from top left) Ms. Lisa A. Coscia, Ms. Pallavi Kumar, Mrs. Kannika Jain

On June 19, 2021, MOHAN Foundation and the Network & Alliance of Transplant Coordinators (NATCO) in association with Transplant Pregnancy Registry International organised a webinar on 'Planned Parenthood Post Transplant.' Ms. Lisa A. Coscia, Senior Registry Research Coordinator-Transplant Pregnancy Registry International, Philadelphia (USA) was the speaker. Two kidney transplant recipients, Ms. Kannika Jain and Mr. Vasu Sundar, shared their experiences of becoming parents post their transplants.

Launch of educational simulation films by MOHAN Foundation in association with Rotary Madras Southwest and Dodla Parthasarathy Reddy and Lalithamma Trust



Rtn. Vijayagopal Reddy (top), Managing Trustee, Dodla Parthasarathy Reddy and Lalithamma Trust and Mr. P W C Davidar, IAS, Retd Additional Chief Secretary giving their reviews of the educational simulation films

MOHAN Foundation launched an educational simulation film series for transplant coordinators on 'Family Approach for Organ Donation' on 22nd May 2021. The films were sponsored by Rotary Madras Southwest (RMSW) and Dodla Parthasarathy Reddy and Lalithamma Trust. Dr. Sumana Navin, Course Director said that these films would play a crucial role in the training of transplant coordinators, especially in MOHAN Foundation's online courses (el.mohanfoundation.org). She added that excerpts of some of these films would be showcased at the 17th Congress of the Asian Society of Transplantation, Malaysia in July 2021. One of the films, 'Shakti – the power within' addressing the issue of directed and conditional donation was screened on the day. Mr. P. W. C. Davidar, IAS, Retd. Additional Chief Secretary, who was present for the launch appreciated the new initiative and the work that was being done by MOHAN Foundation.



Dr. Sumana Navin and Ms. Sujatha Suriyamoorthi receiving the sponsorship cheque of Rs.5 lakhs from Rtn. Vijayagopal Reddy in March 2021. Also seen Rtn. K. V. Prakash, President, RMSW (extreme left) and Rtn. Dr. Ilangovan

Dr. Sunil Shroff awarded the Vocational Excellence Lifetime Achievement Award by Rotary Club of Bombay Seaface for the Rotary year 2020-21



Lifetime Achievement Award being given to Dr. Sunil Shroff by Rotary Club of Bombay Seaface for the Rotary year 2020-21



Vocational Excellence Award presented to Dr. Sunil Shroff

Dr. Sunil Shroff, Managing Trustee of MOHAN Foundation was conferred the Vocational Excellence Lifetime Achievement Award by Rotary Club of Bombay Seaface for his pioneering work in the field of organ donation on May 22, 2021. These awards were for the Rotary year 2020-21.

The online award ceremony was kickstarted by the Club President Mr. Nirmal Doshi and the Convener for the event was Mr. Manishi Vora. A total of four awards were presented by Mr. Sunil Mehra, District Governor, Rotary Club. The selection of the awardees was based on excellence in their vocation while maintaining high ethical standards as well as their contribution to society.

While addressing the audience, Dr. Shroff explained the importance of organ donation and the impact of a community effort to scale up the organ donation rate in India. He appealed to Rotary Club of Bombay Seaface to join hands with MOHAN Foundation to promote the cause of organ donation.

MOHAN Foundation selected as winner in the Health & Wellness category in the 7th Edition of eNGO Challenge Award for the year 2020-21



MOHAN Foundation's 'Technology to enable and augment organ donation' initiative in the Health & Wellness category was selected as the winner in the 7th Edition of eNGO Challenge Award for the year 2020-21. The eNGO Challenge Award, since 2013, is a platform that recognizes, encourages and promotes grassroots organisations and initiatives working for the holistic and inclusive development of communities in development, social and technological innovations.

For the 7th edition, a total of 104 nominations across 9 categories from different countries from South Asia were received during the pandemic, out of which 29 initiatives were selected after the first round of screening for the final evaluation by the Jury. Altogether there are 15 winning initiatives as innovations and best practices for the 7th edition. The Jury was held in April 2021 in a virtual mode due to the COVID-19 pandemic, to identify and select the winners.

Farewell

The Indian Transplant Newsletter and I have been together since its inception in 1998. In a way, the Indian Transplant Newsletter symbolises the organ donation and transplantation journey in India over a quarter of a century. It has been a long and winding road with speed-breakers aplenty along the way, but we have remained undeterred. We have captured the highs and lows, the tears and happiness, the fears and hopes, the courage and magnanimity that embody this field of medicine. It is time now for me to say farewell to MOHAN Foundation, but may all of you dear readers continue on this fulfilling journey with the Indian Transplant Newsletter.



Dr. Sumana Navin
Editor, Indian Transplant Newsletter



“Whilst organ donation rates have improved over the past few years, there is much more to be done. Sadly, around 4 lakh Indians die each year waiting for a life-saving organ transplant. SBI Foundation believes there is great potential to improve India’s organ donation rates through a multitude of interventions including raising public awareness on how individuals can have the power of saving upto 8 lives by merely deciding to pledge their organs. SBI Foundation is proud to have worked together with MOHAN Foundation since the past 3 years to create and strengthen an ecosystem conducive to organ donation. We plan to build on our efforts and scale up the programme strategically to newer geographies to ‘Gift Hope’ to those in need.”

– Mrs. Manjula Kalyanasundaram
MD & COO SBI Foundation

PROJECT **GIFT HOPE, GIFT LIFE**

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Supporting MOHAN Foundation since 2017

- Education & Training of Medical and Para-medical professionals
- National Organ Donation Helpline 24x7 (Toll Free) for dissemination of information to public and patients
- Setting up of Organ donation programme in states with no organ donation activity
- Raising awareness about organ donation among the public

1151 Healthcare Professionals Educated & trained

1500+ Volunteers Educated & trained

30000+ Helpline Calls Counselling

48000+ Public Sensitized about Organ donation

4205 Lives Saved or Enhanced through Organ or Tissue Donation

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