

# INDIAN TRANSPLANT NEWSLETTER

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MULTI ORGAN HARVESTING AID NETWORK

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**Editorial Desk****Organ donation and transplantation myths in movies and television serials have a negative impact on the programme**

Generally medical themes make for winning plots and there are many successful movies and television serials that have used these themes to keep their audience asking for more. 'The Beautiful Mind' depicting schizophrenia, 'The King's Speech' based on a speech impediment and television's 'Grey's Anatomy' that dramatised different areas of medicine are just a few of the many examples. However, themes related to organ donation and transplantation are always projected with sensationalism. It started many years ago with the medical thriller 'Coma' where carbon monoxide was used in the hospital pipes instead of oxygen to kill patients and steal their organs. Just a small problem... carbon monoxide as a gas when it replaces oxygen will not only kill the brain, but will also make all other organs unviable. The same plot was used many years later in a recent Tamil movie called 'Kakki Sattai.'

The success of deceased donor transplantation and the occasional reports of organ commerce has meant that this subject is often misrepresented and over the last five years has been used to create high drama. 'Selling my kidney for money' is used quite frequently in movie dialogues and has become relatively common parlance without even an afterthought in Indian television serials as well.

In the Hindi film 'Andhadhun' many segments show in a very casual manner kidneys, liver, and corneas being sold in India. In fact, it even shows a doctor removing kidneys in an unhygienic environment. In reality, selling kidneys is illegal and kidneys removed in such a manner cannot be used for transplants and will only go into a bin. Another Tamil movie 'Yennai Arindhaal' shows Indians involved in an international organ theft network - killing local people and stealing their organs. What all these movies depict have no scientific, medical, legal, or moral basis. There are movies that range from the downright ludicrous to the realistically implausible. So on the one hand there is a Hindi film 'Diya aur Toofan' where a human brain transplant is shown in the most absurd of settings, while on the other there is the series 'Breathe' on Amazon Prime that shows a father who is a cop killing people (registered donors) of a rare blood group because his son needs a lung transplant.

What most story writers or directors miss is that you can't just kill someone and take their organs and you can't just create brain death by killing someone. Most of these far-fetched plots that revolve around organ donation create fear in the minds of people who may genuinely wish to donate their organs after their death, especially after brain death when one can recycle the whole body.

These plots neither show any requirement for consent or for declaring brain death before organs are removed, nor do they attempt to apprise the audience about the legal framework in the country.

The MOHAN Foundation team finds that whenever this kind of negativism about organ donation is perpetuated by our visual media, it has a profound impact on the minds of our gullible public. The fear psychosis it creates leads to loss of trust in the system. Many people refuse to pick up donor cards after a promotional talk about organ donation and quite a few who have pledged to donate have withdrawn their consent. The censor board too seems to be totally ignorant of the laws that govern the field of organ donation and transplantation in India.

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## 18th International Federation of Kidney Foundations (IFKF) Conference 2018 held in Chennai



*Dr. Suresh Sankar moderating a panel discussion*

The International Federation of Kidney Foundations (IFKF) and Tamilnad Kidney Research Foundation (TANKER) jointly hosted the 18th IFKF Conference, 2018 from 10th to 12th December 2018 at Hotel Savera, Chennai. The International Federation of Kidney Foundations (IFKF) was formed to foster international collaboration and exchange of ideas to improve the health, well-being and quality of life of individuals with kidney disease thereby leading the way for the prevention and treatment of kidney disease. The IFKF has a presence all over the world and helps in establishing more Kidney Foundations and facilitating existing Foundations to become more dynamic and effective. At the inauguration, the Chief Guest Dr J. Radhakrishnan, IAS, Principal Secretary, Health and Family Welfare department, Government of Tamil Nadu spoke about the challenges in handling Chronic Kidney Disease (CKD).



*Delegates from Bhutan with Dr. Georgi Abraham*

There were interesting sessions on CKDu (CKD of unknown etiology) and the possibility of genetic factors compounded by environmental factors having a role to play in this. The talks on policy dialogues in Malaysia and Mexico, as well as CKD screening over 12 years in Jalisco, Mexico emphasised the need to support primary care doctors more and do targeted screening. The sessions on CKD & nutrition – a paediatric perspective, women and kidney health, and living kidney donors underlined the problems faced by vulnerable populations.

There were presentations on Sagliker Syndrome, Chronic Interstitial Nephritis in agricultural communities (toxic nephropathy), Acute Kidney Injury in Africa, and Managing HCV. The sessions on Managing and Fundraising for Foundations, Leveraging social media for Foundations, Role of media in influencing the public about organ donation and transplantation, and Awareness & screening In Tamil Nadu yielded critical insights on how to engage with the public. The consensus session dealt with slowing CKD progression with management of nutrition, obesity, and dietitian support. A Global Renal Internet Course for Dietitians (GRICD) is available.



*Dignitaries at the inaugural function*

The international speakers included Prof. Joel D Kopple - USA, Prof. Gamal Saadi - Egypt, Prof. Kamyar Kalantar - USA, Prof. Tilakavati Karupaiah - Malaysia, Mr. Paul Beerkens – Netherlands, Dr. Guillermo Garcia Garcia – Mexico, Dr. Zaki Morad – Malaysia, Prof. Yahya Sagliker – Turkey, Prof. Marc De Broe – Belgium, and Dr. Esther Obeng - Ghana. The faculty from India included Dr. Manisha Sahay – Hyderabad, Dr. Arpana Iyengar – Bengaluru, Dr. Santosh Varughese – Vellore, Dr. Arvind Conjeevaram – Bengaluru, Dr. Digumathi V S Sudhakar – Hyderabad, Dr. N. Gopalakrishnan, Mrs. Rajalakshmi Ravi, Mr. S. V. Venkatesan, Mr. G. Ananthakrishnan, Dr. Sunil Shroff, and Dr. Sumana Navin, all from Chennai.





## Third Collaborative Conclave for Organ Donation Held in New Delhi



ORGAN (Organ Receiving & Giving Awareness Network) India, an initiative of the NGOs Parashar Foundation & the Vijaya Gujral Foundation, in association with National Organ & Tissue Transplant Organisation (NOTTO) held the Third Collaborative Conclave for Organ Donation with all the NGOs in the field of organ donation on November 29th, 2018 in New Delhi. The conclave was inaugurated by Dr. Vasanthi Ramesh, Director, NOTTO, Directorate General of Health Services, MoHFW, GOI. Dr. Promila Gupta, Principal Consultant, DGHS, MoHFW, GOI graced the occasion as a Special Guest. Dr. Harsha Jauhari (Technical Advisor, NOTP, DGHS, MoHFW, GOI), Dr. Anil Kumar (Additional DDG, NOTP Programme Officer, DGHS, MoHFW, GOI), Dr. Sanjay Agarwal (Professor & Head, Dept. of Nephrology, AIIMS) and Dr. Vipin Kaushal (Nodal Officer, ROTTO Chandigarh) were some of the prominent government dignitaries present at the conclave.

The conclave was attended by around 70 participants from over 13 NGOs and other stakeholders working on organ donation all across India, from states such as Assam, Maharashtra, Gujarat, Rajasthan, Karnataka, Tamil Nadu, Madhya Pradesh, Uttar Pradesh, Odisha, and ROTTO Northern region team from PGI Chandigarh amongst others. This year representatives from the following NGOs from different parts of the country participated in the conclave – MOHAN Foundation, MOTHER, Shine India Foundation, Dadhichi Deh Dan Samiti, A Million Pledges, Zublee Foundation, Apex Kidney Foundation, Muskan Group, Kiran Foundation, Light a Life Reena Raju Foundation, Gift of Life Adventure, NNOS Foundation, and Mindsparks Foundation. Medical professionals from Lady Hardinge Medical College and Safdarjung Medical College & Hospital also participated in the conclave. There were some new faces at the conclave which made it a more diverse and interesting event. Representatives from ROTTO Chandigarh, Kiran Foundation (Bhopal, MP), and Mindsparks Foundation (Lucknow, UP) attended for the first time. Ms. Pallavi Kumar, Executive Director Delhi NCR, MOHAN Foundation was an invited speaker for the session on 'How NGOs can partner with hospitals to encourage and set up an organ donation awareness programme.'

Anil Srivatsa, an organ donor himself, from Gift of Life Adventure who works tirelessly to help organ donors and recipients was present as was the indomitable Reena Raju, a double heart recipient and Founder of Light a Life Reena Raju Foundation. Reena is the Team Manager - India for the World Transplant Games 2019 to be held from 17 – 24 August 2019 in UK. Her Foundation has got India's membership renewed with the World Transplant Games Federation and is actively involved in the preparations for the games. Anyone interested in participating in the games can contact Reena on [reenalightlife@gmail.com](mailto:reenalightlife@gmail.com)

(Source - Dr. Geetika Vashisth, [www.organindia.org](http://www.organindia.org))



Participants at the Conclave

## Tamil Nadu Wins Best State for the 4th time in the Deceased Donation Programme

For the fourth consecutive year, Tamil Nadu bagged the Best State Award in deceased organ donation from the National Organ and Tissue Transplant Organisation (NOTTO), Union Ministry of Health and Family Welfare. Dr. C. Vijaya Baskar, Minister of Health and Family Welfare, Government of Tamil Nadu received the award from the Ministers of State, Union Ministry of Health and Family Welfare, Ashwini Kumar Choubey and Anupriya Patel during the 9th Indian Organ Donation Day programme in New Delhi on 27th November 2018. Additional Secretary (Health) Mr. Nagarajan and Member Secretary of Transplant Authority of Tamil Nadu (TRANSTAN) R. Kanthimathy were present. Dr. C. Vijaya Baskar in his speech said that TRANSTAN, was a first-of-its-kind initiative in the country. So far, 6886 organs were retrieved from 1198 donors in Tamil Nadu. "We have made the organ allocation process transparent, and this is one of the reasons for continuously doing well. We have participation of NGOs and have taken the programme to tier II cities," he added. The State consistently has had a high number of organ donors. At 899 organs that were utilised (November 2017 to October 2018), the State has achieved maximum utilisation of donor organs to benefit end-stage organ failure patients, officials said. The year marked the State's first bilateral hand transplantation at the Government Stanley Medical College Hospital. TRANSTAN coordinated another bilateral hand transplantation at Jawaharlal Institute of Post Graduate Medical Education and Research (JIPMER), Puducherry.

## How and why should we promote organ donation in a country where access to transplantation is heavily biased?



**Dr. Anand Bharathan**  
**Consultant Surgeon, HPB Surgery**  
**Sri Ramakrishna Hospital,**  
**Coimbatore**

India is a country of 130 crore people. Due to individual, social and political will, respectable improvement has been made in literacy rate and health care indices of our country after we gained independence from foreign rulers. However, to this date, a

significant majority of our population lives below the poverty line. Access to qualitative, basic and advanced health care remains unequal both in rural and urban India. Even in urban India, access to good quality health care remains beyond the capacity of the vast majority of Indians. Multiple factors are responsible for the inequality in access to health care. These include rapidly increasing population, poor per capita health care spending by government, hesitation of specialist doctors to serve in rural/remote areas, absence of a well-oiled, tiered public health care system in urban areas, failing to maintain world class standards in many public sector hospitals and consequent mushrooming of corporate health care providers. Corporate health care providers, in many instances, provide high quality health care that our public hospitals struggle to consistently provide. Despite their quality, corporate medical services result in huge "out of pocket" payments and result in "treatment induced poverty" as most people either borrow money or sell their meagre property to fund their health care. Most of our population is not covered by health care insurance that is optimal and adequate despite exhibition of political will to do so.

Liver transplantation in our country exemplifies all of the problems of access to health care that I have outlined earlier. Almost all except two liver transplantation programmes in our country are run by corporate hospitals. As I would detail later, getting a liver transplant operation done in any of these hospitals costs a fortune. Among the few public hospitals in the country that routinely perform liver transplantation, only one provides this service "absolutely free of cost." The poor and lower middle class has literally no access to liver transplantation. With this background, it is amply clear that access to liver transplantation is negligible for the majority of our country's population.

Liver transplantation in corporate hospitals of India costs around INR 2.5 million (USD 35,200). Almost all of the luminaries of liver transplantation in our country are working in corporate hospitals and a significant majority of them are expatriates, who have returned to India to establish highly successful liver transplant programmes. Most of them argue that the cost of liver transplantation in our country is much more economical compared to what it is in the West (where it is 5-6 times more expensive) and that we should really be happy that our people have access to high quality liver transplantation for this cost. But, in a country where the per capita income is a mere USD 1670 and distribution of even this meagre income is very unequal, how can an average Indian afford liver transplantation in a corporate hospital?(1) The most common fate of an economically underprivileged Indian (including children), who has liver failure, is to die without ever getting close to liver transplantation. The best way to perform liver transplantation is doing "deceased donor liver transplantation" (DDLT) as the overall health care impact of this form of liver transplantation is better than "living donor liver transplantation" (LDLT). This is because LDLT involves an operation in a healthy individual, the donor, to remove a part of his/her liver through a major operation. The donor takes time to recover and loses a significant amount of time to get back to normal life. Besides, LDLT is a technically difficult operation. Therefore, the success rate and long-term complications of LDLT remain undeniably poorer than that of DDLT. In view of these reasons, LDLT is almost exclusively performed only in corporate hospitals of India, which are able to aggregate trained manpower resources required for the performance of this complex operation. The more doable DDLT operation remains a less commonly performed operation due to lack of awareness about organ donation and the long-term impact that it could have on the health care economics of the field of transplantation in this country. Unfortunately, this has led to some in corporate medical practice to come to an unfortunate conclusion that LDLT is the way forward in countries like ours!(2)

The intention of this article is to tell readers as to why altruistic deceased organ donation is more important than ever in these times of great inequality between poor and the affordable in access to organ transplantation, despite the fact that the most common deceased organ donor in this country comes from an economically underprivileged section. If we understand this well, it could change the health care economics of the field of organ transplantation in our country in the long term. I also aim to give my views on how this could be achieved.

Promoting organ donation, therefore, most often involves asking families of brain dead (read, most often, Below Poverty Line!) individuals to consider an act of greatest altruism at the moment of their greatest grief. Very often, this is to benefit an economically privileged fellow citizen waiting for transplantation in a corporate hospital, one who is able to afford this expensive care.

Relative technical ease of performance of DDLT could result in a higher number of surgeons and teams getting an opportunity to acquire skills in performance of this operation, if only deceased organ donation increases. This could invariably result in higher number of hospitals setting up teams for performance of DDLTs with successful outcomes. When successful outcome after a widely available procedure becomes commonplace, the corporate health sector is likely to lose the exclusivity that it has on the procedure. Requirement for LDLT will come down or even potentially, disappear. The latter situation is exemplified by very low LDLT rates in many Western countries, as DDLT is widely available there. All this could result in liver transplantation becoming available at a cost that most of the population could afford. Thus, if we need to bring in some equity in access to liver transplantation, promotion of organ donation and thereby, DDLT is the urgent need of the hour. This is precisely the reason why we must put all our efforts and resources into promotion of organ donation, right now!

Even when DDLT becomes widely available, it may not be possible to offer it to all those who need it. Potential reasons could be inability to afford even a small amount of money for the procedure, poor sanitary conditions at their homes that preclude safe post-transplant care and poor social support at homes of the lowest rung of economically underprivileged people. Another round of thought process and activism will be required at that point of time to bring more inclusivism in access to transplantation. The ideal long-term solution for this would be elimination of poverty completely. That is a dream that could take much longer to achieve. The most cost-effective solution for the problem till such time, for diseases of liver could be prevention of liver diseases.

The most common indications for liver transplantation in our country are alcohol related liver failure, non-alcoholic fatty liver disease related liver failure and viral infections like hepatitis B, hepatitis C, hepatitis A and hepatitis E. Most of these causes of liver failure are preventable. The cost of preventing liver transplantation by educational outreach would be much lower than performance and provision of long-term care after liver transplantation. Thus, it is imperative that while we promote organ donation among our people, we are duty bound to simultaneously educate people on the preventive aspect of liver diseases. While governments and private entities will continue to produce, market and sell alcohol always, it is up to people to consume it or reject it. Almost every second transplant that I have been involved in was to treat liver failure due to alcohol abuse.

Most of my peers who perform liver transplantation have shared similar experiences. While promoting organ donation among the masses, we need to emphasise that alcohol is a great health hazard. We need to tell people that alcohol could lead not only to liver failure, but cause major health hazards like pancreatic disorders, cancers in multiple organs and loss of productive workforce. Even if one among 10000 people whom we take this information to listens to our repetitive advice on this, we would prevent one liver transplantation resulting in saving a huge, long-term health care burden.

Fatty liver disease is a lifestyle disorder caused by excessive consumption of carbohydrate or fat-rich food and failure to perform adequate physical activity. We need to make the general public aware that a calorie conscious diet, avoidance of sugar-rich soft drinks and daily exercise could prevent not just liver disease, but also prevent various other non-communicable diseases like cardiovascular ailments. Hepatitis B could be prevented by routine vaccination using a highly effective, economical and widely available vaccine. Hepatitis C could be prevented by careful attention to prevent blood borne infection. Hepatitis A and E could be prevented by widespread access to safe water and food.

Thus, while we promote organ donation with a clear vision and communication of how it could change the landscape of organ transplantation in future, it is imperative for us to strive hard to simultaneously provide information to people on preventive aspects of organ failure. Such a plan would have a far-reaching positive impact on not just provision of donors for organ transplantation, but would go a long way in prevention of organ failure. Most importantly, such a plan is likely to restore public trust and confidence in the process of organ donation and the field of organ transplantation in our country. Doctors in both public and private sector hospitals must be participants in this proposed attempt to restore the confidence of the common man of this country in the integrity of the field of organ transplantation.

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1. World Bank. GNI per capita, Atlas method (Current US\$). 2014.
2. Rela M, Reddy MS. Living donor liver transplant (LDLT) is the way forward in Asia. *Hepatology international*. 2017;11(2):148-51.

## ...Editorial continued

Today there is a trust deficit in the health care system. Therefore, it is important to have films that deal with sensitive issues like organ donation and transplantation shown to a board of experts before they obtain a censor certificate.

Reference - <https://www.medindia.net/news/healthinfocus/kollywood-blockbusters-doing-injustice-to-states-premier-organ-donation-programme-147115-1.htm>





## Say No to (Conditional) Organ Donation...



Mr. Nethaji. J

It is quite unusual to hear from a Transplant Coordinator to “Say No to Organ Donation”. However, when it comes to the “ifs and buts” in terms of consent for a family in considering organ donation, there is larger scope for the family to say no for organ donation. Getting consent for organ donation from a grieving family is considered as success of a coordinator. The consent of the family members should be UNCONDITIONAL and inclusive of

understanding of the concept and process. This case study intends to throw light on the decision-making process by the relatives of potential brain dead donors.

Mr. Manikandan (name changed), a 52-year-old gentlemen was hit by a two wheeler while he was trying to cross the road on a highway. Mr. Manikandan was heading a department in a traditional automobile company in Tamil Nadu. Mr. Manikandan was one of the perfect examples of a middle-aged family man of an orthodox middle class South Indian family with huge responsibilities on his shoulder to shape the future of his son (Rakesh – name changed), an aspiring engineer and a school-going daughter. Mr. Manikandan had extremely good support from his colleagues when it was required. Immediately after the accident, he was taken to a nursing home for the first aid and then transferred to Chennai for further neurological care. He underwent an emergency craniotomy and then shifted to Intensive Care Unit for observation. He was closely monitored for his improvement but could not yield good results. On day 3 his prognosis was too poor and the same was explained to the family. Later in the evening he was clinically diagnosed to have nil brain functions and hence the intensivist decided to conduct apnoea test to confirm the same. The grief counsellor and transplant coordinator accompanied the intensivist in breaking the news to the family. The near relatives and couple of colleagues of Mr. Manikandan were present during the counselling session and as expected the family was shattered to know the current status. The family was given enough time to ventilate and when found comfortable to discuss the possible options left with the family, the concept of organ donation was introduced as one of the options, but not as the first one though. The next of kin requested for time to decide on this as they wished to discuss in detail to take common consensus from family and friends.

Most of the family members were graduates and hence had some information on brain death, but did not have clarity on the process flow followed in brain death and organ donation. They had a lot of misconceptions about the process that added confusion in making a decision on donating. This led to proposing conditions at the later stage of the organ donation process.

This family belonged to a particular community that is well known for orthodox customs and traditions that does not encourage organ donations (due to the belief that the organs would be missing at rebirth). This was raised by a couple of relatives who were present in the initial counselling session. The transplant coordinator clarified the myth. Thereafter, one of the conditions from the near relatives was that if they donated, the information should not be disclosed as the senior members would not be happy about the decision for organ donation. The transplant coordinators said that this was not possible since this could give scope to build distrust on a private hospital and accuse it of working for a vested interest.

Prior to the second set of brain death testing, family members along with a couple of family friends wanted to have clarity on the next plans. The near relatives especially the wife (Mrs. Sangeetha) and the son in principle were not against organ donations, but were reluctant to take a firm decision as it was more of a socio-cultural and religious beliefs of a typical orthodox family and not individual decision. Hence the wife of the deceased approached the transplant coordinator to understand the process involved if she consented for organ donation. After knowing the process and the purpose in terms of giving new lease of life to someone who is ailing from end stage organ failure, Mrs. Sangeetha and Rakesh expressed their willingness to donate their dear one's organs. However the consent did not sound confident from both of them and the reason is quite obvious. This is nothing but the concern that both of them had about what will the rest of the family members especially the in-laws back home and the friends/colleagues of Mr. Manikandan would respond to this. Hence the next round of counselling was organised to take the wishes of the near relatives for a common consensus. The initial outcome was a mixed opinion since the counselling session comprised as many as 15 members. The session ended with the conclusion on consenting (orally) for organ donation but the entire group unanimously agreed to wait until the second set of tests for Brain Death Declaration to confirm the consent status as one among the group raised the concerns on the death status (Brain Death Confirmation).

Hence as a matter of protocol, the information (on potential deceased organ donor) was passed on to the organ allocation authority (TRANSTAN) to identify potential recipients. As a donor hospital, the MLC (Medico-Legal Case) process was initiated with the police intimation and requesting the forensic consultant for post-mortem formalities.

The general difference between consenting and refusing for organ donation can be due to multiple factors. However, clarity on the consent (unconditionally) plays a major role in taking the process to completion of successful donation.

The family requested for clarifications about the process on more than five occasions. Each time they visited the transplant coordinator; the family made a request (because they consented to donate), the coordinator had to turn down. Some of the queries were, we would like to know to whom these organs would be transplanted, will this go to poor patient or to a rich person, how can you ensure that these organs will not be commercialised, Don't inform about this (donation) to some of the other family members if they ask you, this message should not go media at any cost etc. In the meantime, the ICU team was ready to perform the second set of tests. After the second apnoea test confirmed that Mr. Manikandan was declared brain dead, the family (this time not friends or colleagues were available) was oriented on the status and organ donation process was in progress. More than half an hour later one of family friends (little senior though) visited the ICU to know the current status and got upset to know the Mr. Manikandan was already declared Brain Dead and that he was unaware of this. He was one among the few friends who was not so keen on the organ donation process. Taking this as an advantage, he started creating chaos in the ICU, raising his voice against the ICU consultants, and misleading the family who wanted to donate organs. He accused the coordinators of not keeping him in the loop on updating the status and that the hospital was trying to do some sort of illegal allocation of organs. He then brought all the requests that the family had made earlier as demands and later as a condition for donation. The family was a little worried as they did not want to go against someone who had been very supportive all these days and had a key role in getting the benefits from Mr. Manikandan's office. Hence Mrs. Sangeetha and Rakesh too had to join him in raising many irrelevant questions just to satisfy the family friend. The ICU consultant started panicking as the situation was going beyond control. Hence the transplant coordinator had to intervene and call the entire family and friends/colleagues to the counselling room and had to halt the organ donation process and had to firmly say No to Organ Donation. This was something very unusual from the transplant coordinator, as the entire group in the counselling room was expecting that the coordinator would pacify the family but instead he went the other way around. The coordinator made it clear that there is no scope for any conditional donation and there is nothing to hide or manipulate in the organ allocation process as this programme is a transparent one and is being monitored by an independent government body.

There was absolute silence in the counselling room as most of them were aware that one person had made lot of chaos in this process. The transplant coordinator once again stressed that this is a noble cause in saving lives and an act of making the donor as hero. Hence let the decision to consent for donation be altruistic, unconditional and without any second thoughts among the family. The family was advised to take other options apart from organ donation that was discussed during the first counselling session. The family immediately realised their error and regretted the same. However, the transplant coordinator had to end the session there and asked them to wait for further instruction from the consultants. The key family members (along with the one who created chaos) made frequent requests to ICU consultants and to the transplant coordinator insisting on organ donation. After the detailed discussion with all the family members on the protocol and process, the deceased donor organ donation process was restarted.

**At times you have to say No to Organ Donation ...**

*...In the News - National continued from page 3*

## First simultaneous double lung transplant and CABG surgery was done in Bengaluru

Doctors at BGS Gleneagles Global Hospital, Bengaluru performed the state's first simultaneous double lung transplant and coronary artery bypass grafting (CABG) surgery. In the past most people with coronary heart disease were not considered for a lung transplantation. Mr. Ishaq Abdel Hakim Ahmad Sharawi, a 61-year-old man from Jordan, was diagnosed with advanced interstitial lung disease with both lungs permanently fibrosed and damaged. He was evaluated for lung transplantation, but tests showed two major blocks in his heart blood vessels. Since he was deteriorating fast the team led by heart and lung transplant surgeon, Dr. Sandeep Attawar decided to undertake combined lung transplant with heart bypass surgery. He was medically optimised by a team consisting of heart failure cardiologists Dr. Ravi Kumar, Dr. Arul Narayan and transplant pulmonologists Dr. Vijil Rahulan, Dr. Apar Jindal and Dr. Sandeepa HS. On 20th February 2019 there was a donor at Sparsh hospital. The lung retrieval team led by cardiothoracic surgeon, Dr. Bhaskar B V went to Sparsh hospital and the organ was transported to BGS Gleneagles Global Hospital in record time of 20 minutes with the help of a green corridor set up by traffic police. After the transplant was completed, a vein graft was harvested from the patient's leg and a coronary artery bypass surgery was done to bypass the two heart blocks he had. The entire surgery lasted five-and-a-half hours. A team of cardiothoracic and vascular (CTVS) surgeons including Dr. Govini Balasubramani, Dr. Bhasakar B V and Dr. Madhusudana assisted Dr. Attawar in this complex surgery. The patient recovered well and was taken off the ventilator after 24 hours and mobilised on the second day post-surgery.

## 11th Annual Transplant Coordinators' Conference held at St. John's National Academy of Health Sciences, Bengaluru



Dr. Elmi Muller delivering the Swamy Narayan Memorial Lecture

Dr. Dominique Martin delivering her opening remarks at the DICG symposium

Network and Alliance of Transplant Coordinators (NATCO), in association with MOHAN Foundation held its 11th Annual Transplant Coordinators' Conference at St. John's National Academy of Health Sciences, Bengaluru on 3rd and 4th December, 2018. This year's event also saw NATCO and MOHAN Foundation partnering with the International Association of Bioethics to conduct a conference on the theme of 'Emerging Ethical Dilemmas in Organ Donation and Transplantation.' Furthermore, a symposium on 'Organ Donation and Transplantation in a World of Inequality' was organised by the Declaration of Istanbul Custodian Group (DICG) and the Foundation. Both these events were part of the pre-congress sessions that preceded the 14th World Congress of Bioethics.



A panel discussion in progress

Participants at the conference



The Swamy Narayan Best Transplant Coordinator Award being presented to Lt. Col. Sandhya Nair



Ms. Anindita Sabath receiving the Dr J Amalorpavanathan Award for Best Scientific Paper



Dr R K Mani and Dr Roop Gursahani responding to questions from audience

Speakers and Chairpersons in a discussion after a session

More than 200 national and international participants including transplant coordinators, hospital administrators and individuals working towards promoting the cause were present. Speakers, chairpersons and panel members were eminent professionals from the fields of medicine, bioethics, law, media and academia from all over the world. A wide range of topics relating to ethics in transplantation, equity in organ allocation, role of social media, judgments and government orders, organ trafficking, policy making were discussed.

Dr. Elmi Muller - Co-Chair, DICG; Councilor, The Transplantation Society; Past President, South African Society of Transplantation; Professor of Surgery, University of Cape Town, South Africa delivered the Swamy Narayan memorial lecture. Lt. Col. Sandhya Nair, from the Army R&R Hospital, New Delhi and Dr. Bhanu Prakash of MOHAN Foundation received the Swamy Narayan Best Transplant Coordinator award. Ms. Anindita Sabath from MOHAN Foundation received the Dr. J Amalorpavanathan Best Scientific Paper Award for her presentation on 'Perception and attitude towards organ donation among people of Odisha.'

The conference was supported by Jeevasarthakathe – Transplant Authority of Karnataka, SBI Foundation, SBI DHFI Ltd., Tata Trusts, Amar Gandhi Foundation, Zonal Transplant Coordination Centre (ZTCC) Pune, Narmada Kidney Foundation, The Transplantation Society and International Society of Nephrology.



Mr. Bhanu Prakash receiving the Swamy Narayan Best Transplant Coordinator Award – Awareness



## MOHAN Foundation makes presentations at 14th World Congress of Bioethics and 7th National Bioethics Conference in Bengaluru



Rapid Round presentation - Dr. Sumana Navin presenting on 'Should soliciting for organs be allowed through social media'

The 14th World Congress of Bioethics of International Association of Bioethics and the 7th National Bioethics Conference of Indian Journal of Medical Ethics was held from 5th – 7th December 2018 at St. John's National Academy of Health Sciences, Bengaluru. It was co-organised by Forum for Medical Ethics Society (FMES), Sama Resource Group for Women and Health, St. John's National Academy of Health Sciences, and Society for Community Health Awareness Research and Action (SOCHARA).



Ms. Sujatha Suriyamoorthi making her presentation

Dr. Sumana Navin with her poster



Dr. Sumana Navin discussing the ethical challenges in offering organ transplants to foreigners

The theme was **Health for All in an Unequal World: Obligations of Global Bioethics** and it sought to strengthen bioethics in the context of health for all, by providing a relevant and critical platform to advance bioethics discourses and inform praxis - policies, programmes, guidance in the region and globally. Around 800 delegates from different parts of the globe participated in the congress.

The five sub-themes around which intensive plenaries were organised were as follows:

1. Bringing rights and ethics to the centre in the 'Health for All' discourse;
2. Rethinking bioethics boundaries in the context of 'Health for All';
3. Challenges for bioethics in an unequal world;
4. Implications of gender and sexuality in bioethics;
5. Interrogating the construct of marginalisation and vulnerabilities as obligations of bioethics.

The following abstracts from MOHAN Foundation were presented at the congress by Dr. Sumana Navin, Course Director and Sujatha Suriyamoorthi, Manager – Information Systems:

1. Should soliciting for organs be allowed through social media. Authors: Dr. Sunil Shroff, Pallavi Kumar, Dr. Sumana Navin. Accepted for Rapid Round presentation (presented by Dr. Sumana Navin).
  2. Influence of extended family in decision making in donating organs – Ethical Dilemmas. Authors: Sujatha Suriyamoorthi, Dr. Sumana Navin. Accepted for Rapid Round presentation (presented by Sujatha Suriyamoorthi).
  3. Offering organ transplants to foreigners in India - Is this ethically challenging? Authors: Dr. Sumana Navin, Dr. Sunil Shroff. Accepted for Poster presentation (presented by Dr. Sumana Navin).
- Mrs. Lalitha Raghuram, Country Director chaired a parallel track on End of life care ethics that examined topics like Withholding and withdrawing life-sustaining treatment: ethically equivalent?, The ethics of treatment withdrawal after severe brain injury, Health for All? A medicolegal analysis of paediatricians' end-of-life decision making for disabled children in the United Kingdom among others.

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Sd/-

Sunil Shroff

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## MOHAN Foundation invited to National Symposium on Organ Donation and Transplantation at PSG Hospitals, Coimbatore



Dr. R. Kanthimathy, Member Secretary, TRANSTAN at the inauguration

A National symposium on Organ Donation and Transplantation was organised by PSG Institute of Medical Sciences and Research & PSG Hospitals in association with Transplant Authority of Tamil Nadu (TRANSTAN) and Indian Association for Transplant Coordinators (IATC) on 16th February 2019 in Coimbatore. There were about 100 participants that included transplant coordinators from across the country.

Dr. Sumana Navin, Course Director, MOHAN Foundation was invited to be on the faculty for the symposium. Her session focussed on clarifying certain medical, legal and ethical aspects related to brain-stem death certification as per the Transplantation of Human Organs Act. The protocols followed in various ICUs were examined that included total time for testing (brainstem reflexes as well as apnoea test), time of first testing and second testing, and time of death. The need for a uniform definition of death was also discussed.

The debate on 'Should we incentivise the deceased organ donor family' drew impassioned arguments from both the 'For' and 'Against' teams of transplant coordinators. It seemed like the 'Against' team had the audience on its side with Mr. Girish Shetty, Transplant coordinator, Apollo Hospitals, Hyderabad saying that if one were to incentivise, the family would no longer be seen as a 'donor' but a 'vendor.' The segment on multi-organ retrieval brought to life the environment in an Operation Theatre (OT) during a retrieval through a video cast from the Simulation Lab at PSG Hospitals. Dr. S. Swaminathan and



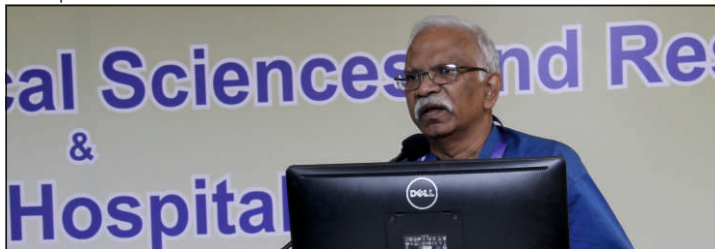
Transplant Coordinators at the Symposium

At the inaugural function, the Chief Guest Dr. B. Ashokan, Dean, Coimbatore Medical College felicitated donor family members, Mr. Muraleedharan and Mr. Anbu Raj. Mr. Muraleedharan donated his wife Mrs. Sarala Muraleedharan's organs and Mr. Anbu Raj donated his son Master. David Raj's organs – a remarkable gift to humanity at a time of unspeakable grief. The other dignitaries present were Dr. R. Kanthimathy, Member Secretary, TRANSTAN, Mr. L. Gopalakrishnan, Managing Trustee, PSG Hospitals, Dr. J. Amalorpavanathan, Former Member Secretary, TRANSTAN, Dr. L. Venkatakrishnan, Professor and HOD, Medical Gastroenterology, PSG Hospitals, and Mr. Nethaji J, Vice President, IATC.

The academic programme covered a gamut of topics that were of key relevance to transplant coordinators. The programme moderators were Mr. Nethaji J, Vice President, IATC and Mr. Mukesh G, State Secretary Tamil Nadu Chapter, IATC. In each of the sessions transplant coordinators shared their experiences and perspectives as well as gave practical inputs on how to tackle challenges in a given scenario.

Dr. B. Joseph John from the department of HPB Surgery & Liver Transplant, PSG Hospitals took the participants through the retrieval process.

The chief organisers of the symposium were Mr. C. B. Chandrasekaran, Manager – Multi Organ Transplantation and Medical Tourism and President IATC, and Ms. Rathi R, Senior Clinical Nurse Specialist, Dept. of Gastroenterology & Multi-Organ Transplantation, PSG Hospitals, Coimbatore. The symposium truly exemplified the theme of 'Working together – the key to successful transplantation.'



Dr. J. Amalorpavanathan, Former Member Secretary, TRANSTAN



## Dr. Rema Menon – It's in her blood...



Dr. Rema Menon

There is no mistaking the passion and zeal that Dr. Rema Menon brings to her work as Head, Transfusion Services, Apollo Hospitals, Chennai. But it is so much more than that, the Blood Bank is where she 'transfuses' hope to not only patients, but also their families. Before she joined Apollo Hospitals in 2005, she worked in different blood banks including the IMA Blood Bank, Kochi, Kerala that was supported by the community. She

witnessed true community spirit here with students contributing money (one rupee each) for the blood mobile. Her sensitivity stems from her work at Kidwai Cancer Institute, Bangalore where she had a baptism by fire seeing leukemic children abandoned by their parents because they were daily wage earners who had to work to provide for the rest of the family.

Talking about the role of the Blood Bank in organ transplantation, Dr. Menon emphasises that it is vital to improving the quality of transplantation since it spans the pre, peri and post-operative period. In fact, it starts with correct blood grouping and Rh typing. It is also important to have an evidence-based blood order schedule for ordering different blood components. In the post-transplant phase, the blood bank is involved in the management of antibody-mediated rejection (therapeutic plasma exchange and adsorption therapy to remove antibodies).

In deceased donation transplantation, the blood bank has to be always prepared for any eventuality. There are no shortcuts here when it comes to giving someone a new lease of life, Dr. Menon says, and adds that in a liver transplantation up to 100 units of blood have been given! The process starts with a minimum stock of blood and blood components being maintained, a quality assurance programme, and staff that is sensitised to the needs of a transplant taking place at short notice.



The Blood Bank team after a training programme

Blood safety has recently taken centre-stage given the scandals in Tamil Nadu, but way back in 2008 Dr. Menon put in place a number of safety measures including leucodepletion to prevent transmission of CMV infection from blood products and NAT testing (for HIV, HBV and HCV). She adds that while it is known that safe blood and blood products are required for many surgical procedures, it is imperative that the public actually understands the process in ensuring safety and the costs involved. Dr. Menon has seen public perception about blood donation changing over the years with growing volunteerism and enormous support for the cause. Social media has played a key role in spreading the message of blood donation among the youth with online campaigns yielding excellent results. Another positive development is that along with blood donation, organ donation is also being promoted.

ABO Incompatible transplantation is gaining popularity and is another area where blood bank interventions are critical to the process.

Dr. Menon elaborates that the antibody titre of the recipient is important. This is evaluated during the pre-transplant workup. If the antibody titres permit intervention, immunomodulating drugs are used, and plasma exchange or



Dr. Rema Menon handing over a training certificate

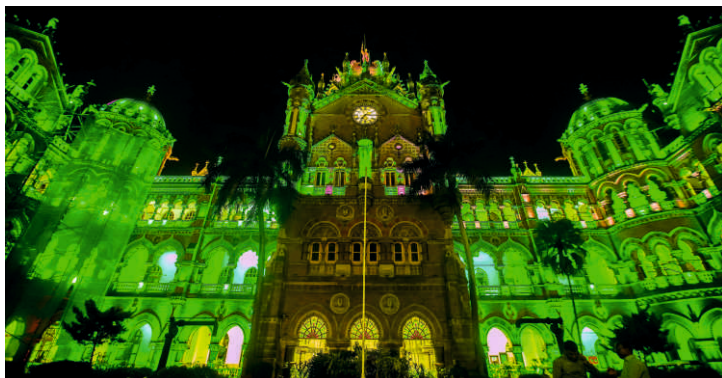
adsorption is done. Four procedures are carried out pre-operatively. Post-operative procedures depend on the immunosuppression that the recipient is being given.

There is one other cause that is close to Dr. Menon's heart as Member Secretary of the Institutional Ethics Committee-Clinical Studies of the Apollo Hospitals – the ethics of living organ donation where she seeks to support vulnerable populations, especially women as living donors – wives, mothers, sisters, daughters. She strongly advocates that an independent living donor advocate be made available in all transplant centres to ensure that it really is informed consent. She feels that psychosocial counselling needs to be strengthened and not made too simplistic with more time spent on family counselling. While she quietly goes about her work in the blood bank, she also makes sure that her voice is heard when she talks about living donor care and follow-up...that too is in her blood.

Dr. Sumana Navin



## Mumbai's Chhatrapati Shivaji Terminus lit up in Green: A Tribute to Organ Donors and their Families on National Organ Donation Day



The iconic century-old Chhatrapati Shivaji Terminus Mumbai (CSTM) railway station, was illuminated in green on 27th November 2018, India's National Organ Donation day, to highlight the cause of organ donation that is conventionally represented by a green ribbon. It symbolises hope for all those waiting for a second chance at life through transplantation. Most importantly, it conveys our gratitude to organ donors and their families for giving the supreme gift of all – the gift of life.

This initiative was undertaken by SBI Foundation and MOHAN Foundation through the project "Gift Hope, Gift Life". #LiveTwice: Be an Organ Donor is a campaign launched by SBI Foundation which aims to spread awareness about organ donation and urge people to consider signing up online at [www.sbif.organdonor.in](http://www.sbif.organdonor.in) or call the National Organ Donation 24x7 Toll Free Helpline. An information booth was also set up by MOHAN Foundation inside the busy station that is a UNESCO World heritage site. Central Railway PRO Mr. Sunil Udasi & Mr. Nixon Joseph, President and COO, SBI Foundation also visited the kiosk, thereby showing their support.



Mr. Nixon Joseph, President & COO, SBI Foundation

## 'Bharat Yatra' by 67-year-old organ donor for Organ Donation Awareness



Mr. Pramod Mahajan on his Bharat Yatra

Pramod Lakshman Mahajan, a 67-year-old farmer hailing from Sangli, Pune, embarked on a journey across India on a two-wheeler to spread awareness about organ donation. In his 'Bharat Yatra' spanning 100 days he rode over 12150 kms across 19 states in the country from 21st October 2018 to 25th January 2019. His expedition was under the aegis of Rebirth Trust, Pune and in association with Emergency Medical Services (108 Ambulance), ROTTO - Mumbai, ZTCC - Pune, Mileage Munchers (Bikers), MOHAN Foundation, Donate Life - Gujarat, Jeevasarthakathe - Karnataka.

Mr. Mahajan shared his experience in the various states he visited. He said that he donated his kidney when an opportunity arose to help an Army jawan (soldier) who had served India in protecting its borders. Mr. Mahajan said, "I was able to impact not just one person but an entire family. The person I donated my kidney to is today the proud father of two sons. Not only have I in a way given life to two more beings, but am able to travel across India promoting organ donation. My health has not suffered one bit. What then is your excuse not to consider organ donation?"



Mr. Pramod Mahajan starting his rally to Puducherry from Chennai



MOHAN Foundation conducted one-week Transplant Coordinators' Training Programmes under the aegis of National Organ & Tissue Transplant Organisation (NOTTO), Directorate General of Health Services, Ministry of Health & Family Welfare, Govt. of India in Bengaluru, Karnataka; Coimbatore, Tamil Nadu; and Jaipur, Rajasthan. The training programmes were supported by the Tata Trusts. With this MOHAN Foundation has completed 60 training programmes with 26 in partnership with NOTTO.

## One Week Transplant Coordinators' Training Programme held in Bengaluru



MOHAN Foundation under the aegis of NOTTO and Jeevasarthakathe - Transplant Authority of Karnataka conducted a one week Transplant Coordinators' Training Programme at the Institute of Gastroenterology Sciences and Organ Transplantation, Bangalore Medical College & Research Institute - Superspeciality Hospital (BMCRI - SSH), Bengaluru from 29th October to 2nd November 2018.

Present at the inaugural function were Sri. Jawaid Akhtar, IAS, Principal Secretary to Govt. of Karnataka, Health & Family Welfare Services as the chief guest, Dr. T. S. Prabhakar, Joint Director (Medical), Department of Health and Family Welfare, Government of Karnataka, Dr. Kishore Phadke, Convener, Jeevasarthakathe and Dr. Nagesh N S,

Director - Institute of Gastroenterology Sciences and Organ Transplant as guests of honour. The MOHAN Foundation team was represented by Mrs. Lalitha Raghuram, Country Director, Mr. Shridhar Hanchinal, Honorary Director, Bengaluru, Dr. Sumana Navin, Course Director, and Ms Ann Alex, Programme Associate. At the valedictory function Dr. Kishore Phadke, Convener, Jeevasarthakathe, and Dr. Sonal Asthana, Senior Consultant – HPB & Transplant Surgery, Aster CMI gave away the completion certificates to the participants.



Mrs. Pragya Prasun, Founder, Atjeevan Foundation sharing her experience



Mrs. Reena Raju, Founder, Light A Life with a participant





## One Week Transplant Coordinators' Training Programme held in Coimbatore



MOHAN Foundation under the aegis of NOTTO and Transplant Authority of Tamil Nadu (TRANSTAN) conducted a one week Transplant Coordinators' Training Programme in Coimbatore from 7th to 11th January 2019. Present at the inaugural function were Dr. B. Ashokan, Dean, Coimbatore Medical College and Hospital as guest of honour and Dr. Ganesh Babu, Deputy Superintendent, Coimbatore Medical College as special guest. The MOHAN Foundation team was represented by Mrs. Lalitha Raghuram, Country Director, Ms. Sujatha Suriyamoorthi, Manager-Information Systems and Ms Ann Alex, Programme Associate. Dr. R. Kanthimathy, Member Secretary, TRANSTAN presented the course completion certificates.



## One Week Transplant Coordinators' Training Programme held in Jaipur

Navjeevan – MFJCF (MOHAN Foundation-Jaipur Citizen Forum) Team conducted a one week Transplant Coordinators' Training Programme at the Sawai Man Singh (SMS) Medical College, Jaipur, Rajasthan from 21st to 25th January, 2019. The training was conducted under the aegis of NOTTO. This is the fourth such training programme conducted by Navjeevan-MFJCF in Jaipur. The training was inaugurated by Mr. Rajiv Arora, Chairman (MFJCF), Dr. Sudhir Bhandari, Principal, SMS Medical College & Hospital. Dr. DS Meena, Medical Superintendent, SMS Hospital, Dr. Ashok Gupta, Medical Superintendent, JK Lon Hospital were also present during the inauguration. The event was graced by Mr. Rakesh Jain who donated his son Mr. Manan Jain's organs and tissues in 2017. MFJCF was applauded by Dr. Sudhir Bhandari for its exemplary work towards creating awareness in the rural parts of Rajasthan and conducting training programmes for doctors and other health care professionals.

At the valedictory function, Mr. Rohit Kumar Singh, Additional Chief Secretary, Government of Rajasthan was the chief guest. Dr. Vasanthi Ramesh, Director NOTTO, Dr. Sudhir Bhandari, Principal, SMS Medical College & Hospital and Dr. Manish Sharma, Nodal Officer, Rajasthan Network for Organ Sharing (RNOS) were the special guests. Mrs. Bhavna Jagwani, Convenor, Navjeevan-MFJCF congratulated the participants on completing the training.



Dr. Vasanthi Ramesh, Director, NOTTO



## MOHAN Foundation's 'Transplant Coordinators' Training Programme' in top three finalists at British Medical Journal Awards South Asia 2018 in Excellence in Medical Education category



The core team of the Transplant Coordinators' Training Programme comprises Dr. Sunil Shroff, Managing Trustee, Mrs. Lalitha Raghuram, Country Director, Dr. Sumana Navin, Course Director, Ms. Sujatha Suriyamoorthi, Manager - Information Systems, Ms. Ann Alex, Programme Associate, and Ms. Pallavi Kumar, Executive Director (NCR). The Transplant Coordinators' Training Programme is supported by Tata Trusts, and the E-learning course (Post Graduate Diploma in Transplant Coordination & Grief Counselling) by SBI Foundation, SBI DFHI Limited and Tata Trusts.



MOHAN Foundation's 'Transplant Coordinators' Training Programme' was in the top three finalists at the British Medical Journal (BMJ) Awards South Asia 2018 in the category of Excellence in Medical Education. A total of 1575 nominations were received from nine countries - Afghanistan, Bangladesh, Bhutan, India, the Maldives, Myanmar, Nepal, Pakistan and Sri Lanka for 10 award categories in phase I. In phase II, 370 nominations were shortlisted. Each entry was assessed for impact, novelty, regional relevance, patient engagement, and scalability. After a final phase of vetting, 30 finalists were picked to make presentations in front of a jury of clinicians, representatives of patients' organisations, and members of the editorial team of The BMJ on 1st December 2018 at The Hilton in Chennai.

Dr. Sumana Navin, Course Director, MOHAN Foundation made the presentation on the 'Transplant Coordinators' Training Programme' in front of the jury. She was accompanied by team members Ms. Sujatha Suriyamoorthi and Ms. Ann Alex. MOHAN Foundation initiated a structured 'Transplant Coordinators Training Programme' in December 2009. This was the first such training in South Asia and 2060 candidates were trained till November 2018. In a pilot project in the Rajiv Gandhi Government General Hospital, Chennai, through the counselling and coordination services of trained transplant coordinators, 66% of families said "yes" to organ donation.

A one-year online course (E-learning with one-week contact session) was launched to help working health care professionals expand their knowledge and upgrade their skills in transplant coordination.



### Online Course for Transplant Coordinators

MOHAN Foundation launches Post Graduate Diploma in Transplant Coordination & Grief Counselling

[el.mohanfoundation.org](http://el.mohanfoundation.org)



## Mrs. Lalitha Raghuram receives "International Women Heroes Award"

The Women Ophthalmologists Society organised a grand conference at Hyderabad International Convention Centre, Hyderabad, on 22nd December 2018 and felicitated Mrs Lalitha Raghuram with the International Women Heroes Award. Mrs. Raghuram delivered the keynote address titled "You are the Clay, you are the Potter." She spoke about her professional journey and life's learnings. The ophthalmologists commended her commitment to the cause of eye and organ donation.



## MOHAN Foundation Transplant Coordinators Felicitated in Tamil Nadu

The Transplant Authority of Tamil Nadu (TRANSTAN) organised an event to honour the families of deceased organ donors in the state on 31st January 2019 at the Tamil Nadu Government Multi Super-Specialty Hospital, Chennai. Dr. C. Vijaya Baskar, Minister of Health and Family Welfare, Government of Tamil Nadu was the chief guest. The other guests present at the event were Dr. R. Kanthimathy, Member Secretary, TRANSTAN, Dr. Edwin Joe, Director of Medical Education, Deans from various Medical Colleges across the state and Dr. Sunil Shroff, Managing Trustee, MOHAN Foundation.

Transplant coordinators deputed to various government medical colleges and hospitals in the state by MOHAN Foundation through a Memorandum of Understanding with TRANSTAN were also felicitated during the event for their contribution.



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