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NEWSLETTER

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MULTI ORGAN HARVESTING AID NETWORK

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Editorial Desk

Kerala and Gujarat Government Orders provide clarity on discontinuation of cardiorespiratory support in a brain death situation

The Government Orders (GOs) issued by the Kerala and Gujarat governments in January and February 2020 respectively provide clarity on discontinuation of cardiorespiratory support in a brain death situation. This could be a gamechanger for the deceased donation programme in the country. For the first time they address the dilemma of intensive care doctors when the relatives say no to organ donation in a brain death situation. In such cases very often the ventilation and support continue and this creates an ethically challenging situation. Majority of the intensive care doctors in India have never been comfortable in such situations. On the other hand, it has been said that brain stem death is defined as death in the context of organ donation as it is mentioned only in the Transplantation of Human Organs Act (THOA), 1994. The Registration of Births and Deaths Act (RBDA), 1969 does not mention brain stem death in its definition of death and hence for many years it has been felt that the RBDA required an amendment to include this. While the Government of India may take time to amend the law, other state governments may consider passing similar GOs to help clinicians overcome their dilemmas and fears.

Salient features of the Kerala GO on Guidelines for Brain Death Certification

- *Brain stem death considered death under Registration of Births and Deaths Act (RBDA), 1969*

It is clear from the scheme of the RBDA that the main purpose of the Act is to maintain and collect information about births and deaths, rather than prescribing how death should be determined. The Rules framed under the Act specify the format for the medical certificate of the cause of death (Form No. 4 under the Kerala Registration of Births and Deaths Rules, 1999). The form requires information about the immediate cause of death as well as other significant conditions of death. It is then clarified that: "This does not mean the mode of dying, e.g., heart failure, respiratory failure etc." The use of the term "etc" in this context is of significance. It suggests that there may be other modes of dying apart from heart failure or respiratory failure. One of these modes is brain stem death and therefore, brain stem death is also considered death under the RBDA, 1969.

- *Role of panel of doctors*

One doctor in the panel has to perform the test and it is mandatory that other panel members have to witness and interpret these tests. All the prescribed tests are required to be performed twice with the minimum interval of 6 hours between the tests "to ensure that there has been no observer error" and persistence of the clinical state can be documented with absolute degree of certainty. It is to be noted that the diagnosis is based only on the clinical examination.

- *Role of ancillary testing*

A neurophysiological or imaging study to prove the absence of electrical activity or blood flow should be carried out if the treating team or panel of doctors who are certifying are in doubt in the diagnosis of brain stem death.

IN THIS ISSUE

Editorial	1
In the news – International	2
In the news – National	3
Interview	4
Invited Article	5 - 6
Conference	7 - 9
Mini Fellowship-Workshop	10
Training Programme	11 - 12
Special event	13 - 14
Awards	15

...continued on page 6



Human Chimerism – Man with Donor’s DNA

Three months after his bone marrow transplant for acute myeloid leukaemia and myelodysplastic syndrome, Chris Long of Reno, Nevada, learned that the DNA in his blood had changed and been replaced by the DNA of his donor, a German man. Four years after his lifesaving procedure, it was found that not only Mr. Long’s blood, but also swabs of his lips and cheeks contained his DNA and that of his donor. Even more surprising was that all of the DNA in his semen belonged to his donor. Mr. Long had become a chimera, the technical term for the rare person with two sets of DNA. The average doctor does not need to know where a donor’s DNA will present itself within a patient. But for a forensic scientist, it’s a different story. The assumption among criminal investigators as they gather DNA evidence from a crime scene is that each victim and each perpetrator leaves behind a single identifying code not two. But this is not always true as seen with Mr. Long. In another case in 2004, investigators in Alaska uploaded a DNA profile extracted from semen to a criminal DNA database. It matched a potential suspect. But the man had been in prison at the time of the assault and it turned out that he had received a bone marrow transplant. The donor, his brother, was eventually convicted.

Third Testicle Transplant in the World done between Twins

A 36-year-old man born without testicles received one transplanted from his identical twin brother in a six-hour operation performed on 3rd December 2019 in Belgrade, Serbia, by an international team of surgeons. The surgery was intended to give the recipient more stable levels of the male hormone testosterone than injections could provide, to make his genitals more natural and more comfortable, and to enable him to father children, said Dr. Dicken Ko, a transplant surgeon and urology professor at Tufts University School of Medicine in Boston, USA who flew to Belgrade to help with the procedure. The operation was only the third known transplant of this type. The first two were performed 40 years ago in St. Louis, also for identical twins, each pair with a brother lacking testicles. The absence of testicles is an exceedingly rare condition, but doctors say that the surgery may have broader applications for transgender people, accident victims, wounded soldiers and cancer patients. But the procedure raises questions about the ethics of transplants that are not lifesaving, and about the possibility of recipients’ someday fathering children with sperm from donors who may not even be related to them.

4th China-International Organ Donation Conference held in Kunming, China

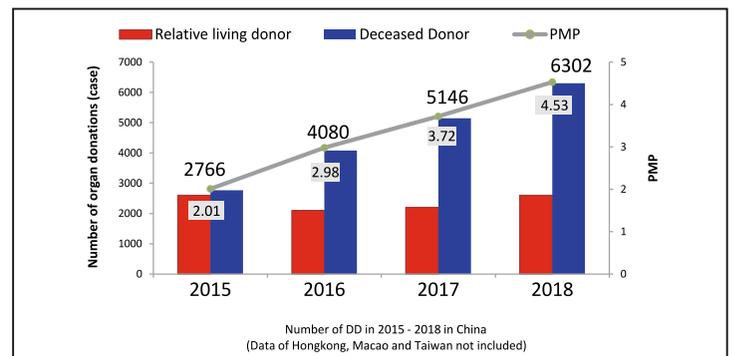
The 4th China-International Organ Donation Conference (CIODC) & the Belt & Road Symposium on Organ Donation Development and International Cooperation was held in Kunming, China from

6th to 8th December 2019. The conference was held at the Haigeng Conference Center in Kunming of Yunnan Province. Dr. Sunil Shroff, Managing Trustee, MOHAN Foundation was invited to attend the conference. He was also invited to give a talk at the Red Cross Society of China that coordinates organ donation in Kunming and share his experience of the deceased donation programme in India. Dr. Avnish Seth, Director, Fortis Organ Retrieval and Transplant (FORT) was also invited to the meeting.



Dr. Vijayanand Palaniswamy, Intensive Care Specialist, Australia with Dr. Sunil Shroff, Managing Trustee, MOHAN Foundation

China has shown remarkable progress in deceased donation in the last few years (graph given below). The conference was to reiterate their stand toward ethical practices in deceased donation. There were almost 100 international invitees to the meeting with representation from The Transplantation Society, WHO and other International societies and a declaration was signed in line with the WHO principles to promote deceased donation in the ‘One Belt One Road’ countries.



At the Red Cross Society of China, Kunming Branch

Odisha records its First Deceased Donor Transplant



Team from Apollo Hospitals paying their respects to the deceased donor

Odisha achieved a major milestone in kidney transplant on 4th February 2020, when the doctors of SCB Medical College and Hospital (MCH), Cuttack and Apollo Hospitals, Bhubaneswar did the first-ever deceased donor transplant in the state. The kidneys were donated by the family of a young girl, P. Priyanka Rani Patra from Ganjam who was in Apollo Hospital ICU since 26th January after sustaining injuries in a road accident. She was identified as brain dead by the ICU team from Apollo Hospitals led by Dr. Sharmili Sinha. After receiving the consent from the family, Apollo Hospitals informed the State Organ and Tissue Transplant Organisation (SOTTO) at SCB MCH on 3rd February 2020. Once the procedures were completed as per the Transplant Act, the retrieval was started by Dr. Samirandas Adhikari, Dr. K. P. Satapathy and team from Apollo Hospitals with Dr. Sabyasachi Panda from SCB MCH in the presence of Prof. Datteswar Hota and Prof. Chittaranjan Kar.

"Once both kidneys were retrieved, it was allocated to patients in the waiting list of Apollo Hospitals and SCB MCH prepared as per the NOTTO guideline by Dr. Rudrasis Samal, (Joint Director, SOTTO) and approved by Kidney Committee," a press release read. The kidney from Apollo Hospitals was transported to SCB MCH by road. The transplant operation was undertaken by Prof. Hota with his team at SCB MCH and Dr. Samirandas Adhikari and his team at Apollo Hospitals. Others who helped in coordination were Dr. Jyoti Parija (Assistant MS Apollo Hospitals), Subrat Sahu (Transplant Coordinator, Apollo Hospitals) and his team, Suman Singh (Consultant, SOTTO), Anindita Sabath (Transplant Coordinator, SOTTO), Ramakrushna Panda (Programme Assistant, SOTTO) and Hare Krushna Panda (Transplant Coordinator, SCB MCH). At present both the recipients are doing well, the press release added.



Apollo Hospitals staff paying their respects to the deceased donor

Coimbatore Hospital performs successful kidney transplant involving haemophilic donor and recipient

Doctors in a Coimbatore hospital transplanted a kidney in a 12-year-old boy suffering from haemophilia, a blood disorder that does not allow it to clot like it is supposed to. What made the case rare was that the kidney donor, who was the boy's maternal uncle, also suffered from haemophilia. The surgery was performed by replacing the missing protein (clotting factor), which restored the clotting mechanism temporarily, for 10 days, by which time the wound had healed reasonably well. Doctors in Kovai Medical Centre and Hospital, where the surgery was performed, said they were yet to come across a case of renal transplant in medical literature where the kidney recipient and donor both suffered from haemophilia.

Doctors said the main risk of operating on such patients is uncontrollable bleeding and the burden of maintaining two patients with the issue. However, faced with no other viable option, they decided to go ahead. The boy had a rare genetic condition called Alport syndrome, which led to the kidney failure. The boy was advised an immediate transplant and his maternal uncle, whose HLA type and blood matched his, came forward to donate one of his kidneys. Both the donor surgery and the recipient surgery went off well without any complications. The donor was discharged five days after the surgery and the recipient went home 10 days after the surgery, with normal kidney function.

Organ transplant to get a major boost in Rajasthan

The Chief minister of Rajasthan, Mr. Ashok Gehlot allocated Rs. 14,533 crores to the health sector for developing infrastructure, enhancing human resources, improving delivery of services, and reducing out-of-pocket expenditure. This year, apart from focusing on Nirogi Rajasthan scheme, the state government has given impetus to the organ transplant programme.

As of now, Sawai Man Singh (SMS) Hospital, Jaipur has facilities for organ retrieval from brain dead patients. Now, the state government will develop organ retrieval centres in Udaipur, Kota, Ajmer and Bikaner. Also, Jodhpur's Mathuradas Mathur hospital has been authorised for organ transplant. Mr. Gehlot has also proposed a surgical gastroenterology department for developing liver transplant facility in SMS Hospital. For this purpose, the state government has signed a Memorandum of Understanding (MoU) with the Institute of Liver and Biliary Sciences, New Delhi.

Mrs. Vasundhara Raghavan, CEO, Kidney Warriors Foundation



Mrs. Vasundhara Raghavan

Vasundhara receiving The La Renon TANKER Foundation For the Sake of Honour Award

Her diminutive frame belies the fierce energy that she brings to the patient advocacy group for kidney disease that she heads. It is called Kidney Warriors Foundation, and Mrs. Vasundhara Raghavan is the CEO and Warrior-in-Chief! It is involved in improving the lives of kidney patients, ensuring that their voices are heard, and extending financial support to them. We watched Vasundhara as she received The La Renon TANKER Foundation For the Sake of Honour Award from the Chief Guest Mr. M. M. Murugappan, Chairman, Murugappa Group and Dr. Georgi Abraham, Founder Trustee, TANKER Foundation. The occasion was TANKER Foundation's 27th Annual Charity & Awards Nite held on 25th January 2020 in Chennai. Her eyes shut briefly, maybe in prayer or giving thanks, as the citation was being read, but one could feel her marshalling her forces to continue to wage war against chronic kidney disease. The citation applauded her spirit of dedication and determination in tirelessly striving to make a difference in the lives of patients and their families. Earlier she delivered the Mrs. Malathi Venkatesan TANKER Foundation Memorial Lecture on 'The Kidney Warriors – A new outlook to the kidney disease challenge.' She emphasised that people with chronic kidney disease were isolated and carried a much heavier burden than the general population. They needed support that was warm, genuine, and reassuring. And that was what the Facebook group The Kidney Warriors provided.

Through her books, Vasundhara has addressed the many issues that chronic kidney disease throws up. In her first book, *Shades of Life* she narrates and reflects on her son Aditya's battle with chronic kidney disease, dialysis, two transplants and the physical and mental toll that all of this takes on the patient as well as the family. Vasundhara battled cancer, and then went on to donate a kidney to Aditya. This first kidney transplant worked well for six-and-a-half years, but then he had to go back on dialysis again. He received a second kidney transplant with his elder brother, Dhananjay being the donor. Vasundhara talks about Aditya's 'never-give-up' spirit being their guiding light. There is a poignant description in the book of a moment shared by the two brothers and their mother on Venice beach, Los Angeles soon after the loss of the first kidney transplant.

She writes, "We stood looking at the distant horizon beyond the wide expanse of blue sea, the sky streaked with shades of orange, red and yellow as the sun shied away, ready to bid me goodbye. This image imprinted itself in my mind's eye as one depicting the shades of life: Hope – seeing the wonderful waves soaring high as if wanting to touch the soft, white feathers of the seagulls; Anger – knowing that life was filled with trials and need for enormous energy to overcome them; Love of Life – deep sorrows caused by failures, happiness drawn from acceptance, and paying homage to the spirit of life. Success is learning to accept life with all its limitations and live cheerfully."

Her second book 'Kidney Warriors' is a compilation of 56 hard-hitting stories of people who battled chronic kidney disease, people on dialysis, people who had a transplant, people who lost a transplant – each of them has a unique story to share, and these stories offer us a chance to understand their minds and hearts, and to draw courage from them. Vasundhara says losing a kidney after a transplant is akin to losing someone close to you. A bald "how did it happen" needs to be replaced with "understanding" the need for privacy. Her third book is titled 'Who Lives, Who Dies with Kidney Disease.' Kidney Warriors Foundation has also brought out two handy books on diet and kidney disease called 'Nutritional Secrets' with easy to follow flow charts, simple tips for a balanced renal diet, and 120 recipes completely evaluated.

Recently Vasundhara was appointed to represent the patient group in the reconstitution of the National Oversight Committee (NatCom) for the National Dialysis Programme. She says emphatically that patient and caregiver groups need to be involved when organ donation and transplant laws are being framed, that more young nephrologists need to be part of transplant teams to be better able to help patients with the disease. She flags the need for job opportunities and flexi-time in employment for patients with CKD so that they can continue to work and feel purposeful in society. It is also important she adds to have subsidised Reverse Osmosis (RO) plants in all dialysis centres with quality checks, decrease cost of dialysers, and facilitate better training of dialysis technicians. Kidney Warriors Foundation has recently embarked upon an educational series of talks and interactions with doctors and patients in different cities in India.

What started as a Facebook group in 2014 with Vasundhara reaching out to others suffering from the agony of 'why me', the guilt of 'if only' has evolved into the Kidney Warriors Foundation in 2017. This indefatigable tribe of more than 2000 warriors has fought many battles against chronic kidney disease - sometimes a victory, sometimes a loss, but they soldier on...

- Dr. Sumana Navin

Preventive health care for liver diseases - unfolding an ethical dilemma and vision for future



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

Are we in the health care profession?

My mentor, Prof. V. Sitaram says that doctors are not in health care, but in the sick care profession. We live in a socio-politico-economic system where factors which cause diseases are allowed to exist, often thrive. Ensuing enormity of preventable diseases has buckled the public sector health care of India, resulting in unfortunate and seemingly irreversible takeover of health care by corporate hospital chains that aim at quality health care and shareholder return rather than empathise with suffering poor people afflicted with treatable diseases, but cannot afford it.

It is exciting to be in liver transplantation.

Swallowing my entrenched cynicism towards corporate hospitals, I moved from CMC, Vellore to a corporate hospital to train and subsequently work in liver transplantation. While the field was full of opportunities to explore and earn a luxurious livelihood, socio-economic discrimination in access to liver transplantation was agonizing. After a long thought process and precipitated by the death of a bright 11-year-old child with Wilson's disease who died due to lack of finances, I did something that was long overdue. I left my job.

Is this a judicious system?

The whole system of health care looked wrong. There was no justice, vision, economic or ethical sense. Government Stanley Medical College and Hospital, Chennai was the only centre in our country offering liver transplantation free of cost, that too with the benevolence of a corporate hospital team.

Stepping back and introspection. Are we missing the elephant in the room?

Part-time work for a team in Bangalore that provided affordable liver transplantation collapsed soon for many reasons. Reading books on health care economics and meeting many selfless "beacons of hope" in our country's injudicious health care system like Dr. Ravikannan in Silchar, Dr. Anju Kataria and Dr. Yogesh Jain in Ganiyari, Dr. Lalitha and Dr. Regi in Sittilingi, lucidly changed my views of health care. Affordable liver transplantation would be the worst possible solution for liver diseases. We were missing the elephant in the room.

The demand-supply gap

While about, 2,59,749 patients die annually in India due to liver diseases, 1800 liver transplants were performed in 2018.

Co-morbidities, socio-politico-economic factors affecting organ donation and unaffordability are among reasons for fewer liver transplantations. Deceased organ donation rate in our country was a pathetic 0.65 per million population compared to 48.3 per million population in Spain in 2018.^[1] This is the main reason for sale of living donor liver transplantation for a premium cost.

Is it possible to simply increase organ donation & hope for a change in access to care?

MOHAN Foundation has been promoting deceased organ donation and training grief counsellors. Even with higher organ donation rates, corporate Indian healthcare may not allow its premium product, liver transplantation to have a much-needed free-fall. Good-willed liver transplant teams could call this thought pessimistic. Among them, those who truly understand healthcare economics are hardly any.

Socio-economic impact of liver disease

About 2.5 lakh people die annually and prevalence of liver disease could be 10 times that, about 25 lakhs, officially. Alcohol is the main cause and young people are most affected. Family income and meagre savings corrode as jobs of patients and often, the spouse who looks after him are lost. Children often drop out of school. Indirectly, over 1 crore Indians lose their livelihood. The social fabric of affected families corrodes, a breeding ground for crime is created. Multiple hospitalisations are required to treat complications of liver disease and each could cost INR 30,000/- to 100,000/-. About INR 15-30 lakhs are commonly spent, before the disease progresses over years and death comes as an untimely relief. This is often the life-time saving of a middle-class Indian family, leave alone the poor. Munificence of the government to offer insurance-funded liver transplantation is an unpremeditated decision as most affected people do not even have a clean house to live in after liver transplantation. Even if cost comes down or is publicly funded and every liver transplant centre becomes 10 times more productive (ambitious target), we will only perform 18,000 transplantations every year, mostly on those with safe housing. The rest will still die.

Alcohol economy

Alcohol is a USD 52,575 million economy in our poor country, mostly serving private enterprises.^[2] State agencies like TASMAL market it and mostly lease sales outlets to private players. The Governments of Tamil Nadu and Kerala earned INR 21,800 crores and INR 8,000 crores respectively in 2013 by alcohol sales. The immense moral, health care, financial and social corrosion that alcohol causes to about one crore citizens cannot be offset by this money. Acute and chronic pancreatitis, family disruption, mental health disorders, homelessness and crime unleashed by alcohol call for urgent bureaucratic and political reassessment of their ill-informed views on alcohol economy.

Food industry and fake news

Non-alcoholic fatty liver disease (NAFLD) is the second most common cause of liver disease and transplantation in our country. Unlike alcohol outlets, the food industry is omnipresent. Coca-Cola, Pepsi, confectionery industry and omnipresent sweet outlets sell us sugar, the sweet mediator of death in many forms. Unrestricted access to these food leads not just to fatty liver and liver failure, but causes diabetes mellitus, cardiovascular and cerebrovascular diseases and obesity making India the non-communicable disease capital of the world. Innumerable advertisements and movies show healthy and socially admired Indians endorsing these products. This fake news about products that bring ill-health is shown hundreds of times daily.

NAFLD medications- You are not the consumer. You are the product!!

Medicines for treating NAFLD are about to enter the market. Associated non-communicable diseases like obesity, diabetes and cardiac disorders may not be addressed by these medicines. How could we substitute physical exercise and healthy diet with medications that cost billions each year? For the food industry, we are not the consumer. We are the product! Food industry produces unhealthy humans and sells this product to hospital and pharma industry.

Vaccination and clean food/water

Vaccination for hepatitis B is part of India's universal immunisation programme from 2002 and is a spectacular illustration of what political and bureaucratic will could achieve in preventive health care. We should appreciate the Government of India's efforts for "Swachh Bharat Abhiyan" which has a great potential to reduce incidence of many food and water-borne diseases like hepatitis A and hepatitis E.

How and where do we educate the public? Funding? How will we measure the impact?

We now know that an urgent need to prevent liver diseases exists. Government does not have an exclusive programme to do this.[3] We have to relentlessly pursue policy makers to take note, project alcohol as a socio-economic disaster, seek regulation in advertisements of food industry and expand Swachh Bharat Abhiyan. Conscientious doctors have to urgently work with and also separately from the government for this. It could be a difficult task to get funding for such a non-governmental preventive project as its impact could be difficult, though not impossible to measure.

Vision for the future

We have to engage social workers, NSS, Scouts and any potential volunteer to take the message to their circle of influence in villages, schools, colleges, public and private enterprises of India. Doctors could train the inspired volunteers using standardised presentations that could be adopted to local requirements. I appeal to all liver

transplant teams to take up the cause of preventive health care and work in their spheres of influence to influence both the public and the policy makers. We must create a public movement that runs by the efforts of inspired individuals and their collective action rather than with one that runs on the altruism of financial donors or through a government-run program.

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Editor's note: This article is based on a lecture delivered at 'Bioethicon 2020', a CME on Bioethics organised by MOSC Medical College, Kolenchery, Kerala.

...Editorial continued from page 1

• Time of death

The time of death is the time the arterial pCO₂ reached the target value in the second apnoea test.

• Discontinuation of cardiorespiratory support

The family member/caregiver should be provided with brain stem death confirmation report signed by all the four members of the brain stem death certifying team. All treatment including cardiorespiratory support must be discontinued once brain stem death is pronounced.

Salient features of the Gujarat GO on Brain Stem Death Declaration Guidelines

It is based primarily on the Kerala GO on Brain Death Certification. The significant differences are that the Gujarat GO does not comment on the RBDA, 1969, and while the Kerala GO makes no mention of organ donation in its algorithm, the Gujarat guidelines incorporate consent/no consent for organ donation. The guidelines state, 'After grief time, the near relatives of the deceased person may ask for organ donation of brain stem dead person. If family agrees for organ donation and signs Form 8 (www.notto.gov.in), the cardiopulmonary support and end of life care must continue till the organ procurement procedure takes place. If family does not agree, all treatment including cardiorespiratory support must be discontinued once brain stem death is pronounced.'

Both GOs caution that rather than ordering ancillary tests, physicians may decide not to proceed with the declaration of brain stem death if clinical findings are unreliable.

The Kerala GO in its entirety is available at www.knos.org.in

12th National Annual Transplant Coordinators' Conference in association with CMHS held at IIM, Ahmedabad



Dignitaries lighting the lamp as part of the inaugural function



Prof. Rajesh Chandwani, Chairperson, CMHS-IIMA being felicitated by Dr. Sunil Shroff, Managing Trustee, MOHAN Foundation

The Network and Alliance of Transplant Coordinators (NATCO), in association with MOHAN Foundation and the Centre for Management of Health Services (CMHS) - Indian Institute of Management (IIM) Ahmedabad organised the 12th National Annual Transplant Coordinators' Conference at the IIM Ahmedabad campus on 30th November and 1st December 2019. The theme of this year's conference was "Let's Collaborate," with a focus on exploring public-private partnership options for organ donation in India. Experts from government, industry, transplant professionals, and public health specialists were invited to be part of this focus discussion. The conference had close to 150 Transplant Coordinators, working in public and private hospitals, participating from across the country.



Dr. Sonal Asthana (centre) delivered the Swamy Narayan Memorial Oration



Ms. Rajinder Kaur of Chandigarh receiving the Swamy Narayan Best Transplant Coordinator Award from Mr. K. Raghuram, Dr. Sunil Shroff and Mrs. Lalitha Raghuram



Prof. Errol D'Souza, Director, IIM Ahmedabad speaking during the inaugural function

The inaugural saw Dr. Errol D'Souza – Director, IIM-A, Prof. Rajesh Chandwani – Chairperson, CMHS, Mr. PWC Davidar, IAS – Former Principal Secretary, Govt. of Tamil Nadu, Dr. Sunil Shroff – Managing Trustee, MOHAN Foundation, Dr. Vishavdeep Goyal – Chief Operating Officer, Apollo Hospitals, Ahmedabad, and Mr. Ajith S Babu – Milaap lighting the ceremonial lamp. Dr. Shroff, Mrs. Lalitha Raghuram – President, NATCO, Dr. D'Souza and Mr. Davidar addressed the gathering. Dr. Hemal Kanvinde – Secretary, NATCO delivered the NATCO report.

With a focus on policy perspectives, this year's conference featured many eminent speakers including Dr. Jayanti Ravi, IAS – Principal Secretary, Health & Family Welfare, Gujarat and Dr. Rakesh Gupta, IAS – Project Director, CM's Good Governance Associates Program, Haryana; Nodal Officer – Beti Bachao Beti Padhao CM Office, Haryana.

The Swamy Narayan Memorial Oration was delivered by Dr. Sonal Asthana, Clinical Lead HPB Surgery and Multi-organ Transplant, Aster CMI Hospital, Bengaluru. His lecture highlighted the need to make the transplant programme inclusive, affordable and accessible.

Ms. Rajinder Kaur, Transplant Coordinator - PGIMER, Chandigarh bagged the Swamy Narayan Best Transplant Coordinator Award for the year 2019. Ms. Priti Jain - Alexis Hospital, Nagpur and Ms. G Lakshmi – CARE Hospital, Telangana also won awards for best transplant coordinators, sponsored by Abhayam Kidney Care Trust. For the first time, a new award was instituted – the Milaap-MOHAN-NATCO Best Transplant Coordinators' Award, which recognises efforts towards fundraising for economically backward patients. Five transplant coordinators from different parts of the country were the recipients of the award.

Conference



Special appreciation award bestowed on Ms. Pallavi Kumar, Executive Director (Delhi-NCR), MOHAN Foundation



Faculty and delegates at the 12th National Annual Transplant Coordinators' Conference



NATCO Executive Committee Members



The delegates during a session

Ms. Pallavi Kumar, Executive Director (Delhi-NCR), MOHAN Foundation was felicitated at the event for her extraordinary achievements that included scaling the Everest Base Camp and Mt. Kilimanjaro in 2018 and 2019 respectively as a tribute to organ donors and commitment to the cause.

Dr. Geetika Vashisth's paper titled 'In-depth analysis of the socio-demographic profile of people from across India who pledged to be organ donors, and the medium of information that they interacted with leading to them pledging' bagged the Dr. J. Amalorpavanathan Best Scientific Paper award. A poster on 'Knowledge and attitude on organ donation among auto- rickshaw drivers in Chennai' submitted by MOHAN Foundation won the award in the poster category.

MOHAN Foundation participates in the 15th Congress of ISODP in Dubai



Ms. Pallavi Kumar, Mrs. Lalitha Raghuram and Dr. Sunil Shroff representing MOHAN Foundation at ISODP



Mrs. Lalitha Raghuram presenting on Utilizing Metro station for Organ Donation Awareness - a first ever initiative in India

MOHAN Foundation participated and presented at the 15th Congress of the International Society for Organ Donation and Procurement (ISODP) held from November 14-16, 2019 in Dubai, United Arab Emirates and hosted by the Saudi Center for Organ Transplantation and the Emirates Medical Association Nephrology Society. The Congress was attended by Dr. Sunil Shroff, Managing Trustee, Mrs. Lalitha Raghuram, Country Director, and Ms. Pallavi Kumar, Executive Director (Delhi-NCR). Mrs. Lalitha Raghuram presented on "Utilizing Metro station for Organ Donation Awareness – a first ever initiative in India" and "Organ Donation made possible through a toll- free service- the new facet of an Organ Donation Helpline in India." Ms. Pallavi Kumar made a presentation on guidelines for "Organ Donation by Foreign Donors in India."

First International Conference on Brain Death Donor Transplant Programme in Chitwan, Nepal



Dr Sunil Shroff making a point at the panel discussion on how to get started in Nepal

MOHAN Foundation helped in designing and planning the First International Conference on Brain Death Donor Transplant Programme that was held at the College of Medical Science (COMS) in Chitwan, Nepal on January 31 and February 1, 2020. Dr. Sunil Shroff, Managing Trustee and Ms. Pallavi Kumar, Executive Director (Delhi-NCR) were resource persons for the workshop.



The organising committee along with visiting faculty

The conference was organised by the Transplant Unit of College of Medical Science and Teaching Hospital. The organ transplant programme has moved ahead since it started in Nepal in 2008. College of Medical Science has been the first to undertake renal transplant outside the capital in 2015, on the day Nepal was struck by a great earthquake.

MOHAN USA sets up Information Booth at the Annual Meet of American Society of Nephrology in Washington D.C.

The annual meeting of the American Society of Nephrology (ASN) was held in Washington D.C., from the 6th to the 10th of November, 2019. It is the biggest annual gathering of Nephrologists in the world with over 14,000 attendees arriving from all over the globe.

MOHAN USA exhibited at the event as a registered non-profit. The booth was manned by Dr. Nidyanandh Vadivel from Seattle, Dr. Anirban Bose from Rochester, Mr. Adinarayana Dasika from



Dr. Anirban Bose, Mr. Adinarayana Dasika, Dr. Nidyanandh Vadivel manning the MOHAN USA information booth

New Jersey and Dr. Hemal Kanvinde from MOHAN Foundation, Chennai, India. The booth displayed information about the Foundation's inception, growth and achievements over the last two decades.

The display generated substantial interest amongst a lot of attendees. While some knew about MOHAN Foundation's work, they were very impressed to learn the details of the Foundation's achievements. Others had no idea such an organization existed and were very moved to learn of all the work the Foundation has done to promote deceased organ donation in India. They were particularly appreciative of the educational campaigns carried out by MOHAN Foundation to sensitize a population as diverse as India's and the training afforded to transplant coordinators and grief counselors.



Visitors at the MOHAN USA information booth

A substantial amount of interest was from delegates from other developing nations who could readily identify with the resource crunch faced by MOHAN Foundation in India and were very interested in learning more about the Foundation's playbook to maximize the utilization of available resources. Health-care professionals from countries such as Bangladesh, Pakistan, Egypt, Tunisia, Colombia, Nigeria, and Sudan were amongst others who stopped by the booth to learn more about MOHAN Foundation's activities and the reasons for its success over the years in promoting deceased organ donation.

- Dr. Anirban Bose

Mini Fellowship-Workshop

Mini fellowship at Gift of Life Institute, Philadelphia to improve organ donation and transplantation



Dr. Hemal Kanvinde (R) with Dr. Lisa Corsica of Transplant Pregnancy Registry, GOLI

Dr. Hemal Kanvinde, Quality Assurance Officer of MOHAN Foundation (MF) underwent Gift of Life Institute's (GOLI) Mini Fellowship in Organ Donation and Transplantation from 28th October to 7th November 2019 in Philadelphia, USA. The Mini Fellowship was sponsored through an educational grant from MOHAN, USA. It comprised personal interactions, observational learning, and an organ donation and transplant summit.

Gift of Life Donor Program, Philadelphia is one of the largest Organ Procurement Organizations (OPO) that covers deceased organ and tissue donation in the tristate zone of eastern Pennsylvania, Delaware and southern New Jersey. Gift of Life Donor Program manages every facet of the donation process, coordinates the recovery of organs and tissues, and allocates the organs to suitable recipients as per UNOS (United Network for Organ Sharing) allocation policies.



(L to R) Donor Mother, Dr. Hemal Kanvinde (MF), Transplant Coordinator (GOLI) at ICU Nurses Meet

Many parts of their work were explained through interactions with the staff. The observational visits were at Thomas Jefferson University Hospital, Virtua Memorial Hospital, and Einstein Medical Center. During the fellowship, Dr. Hemal was housed at the Gift of Life Family House. This is part of the services provided for the transplant patients and their caregivers at affordable prices. It provides lodging, food, transport and other support services. Volunteers come and prepare hot evening meals for transplant patients and families. She said that the Mini Fellowship was a great learning experience and expressed her gratitude to Mr. Howard M. Nathan, President and CEO, Gift of Life Donor Program, and Ms. Theresa Daly, Director, Gift of Life Institute.

National Workshop for Strengthening of Organ Donation and Transplantation Process held in Indore, Madhya Pradesh



Panelists for the interactive discussion on donor management - (L to R) Dr. Urvi Shukla, Dr. Rakesh Gupta, Neurosurgeon, M.G.M Medical College, Dr. Arora, HOD, Anaesthesia, M.G.M Medical College, and Mrs. Uma Jhawar, MK International Eye Bank



Dr. Sunil Shroff, Managing Trustee, MOHAN Foundation moderating the activity on personnel involved in deceased organ donation in a hospital

The State Organ and Tissue Transplant Organisation (SOTTO) – Madhya Pradesh and M.G.M Medical College, Indore in association with MOHAN Foundation and Network and Alliance of Transplant Coordinators (NATCO) organised a 'National Workshop for Strengthening of Organ Donation and Transplantation Process' on 16th December 2019 at M.G.M Medical College, Indore. The workshop was also supported by the Indore Society for Organ Donation. The day-long workshop had 110 participants that included ICU doctors and nurses, neurosurgeons, general physicians, and representatives of NGOs. Dr. Urvi Shukla, HOD, Intensive Care and Emergency, Symbiosis University Hospital and Research Centre, Pune was the expert faculty member. At the valedictory function, Mr. Akash Tripathi, IAS, Commissioner of Indore emphasised that it was important to have processes in place to facilitate deceased organ donation. Dr. Jyoti Bindal, Dean and CEO, Appropriate Authority-SOTTO-MP and M.G.M. Medical College, and Dr. A. D. Bhatnagar, Medical Superintendent, M.G.M. Medical College expressed their support.



Dr. Urvi Shukla, HOD, Intensive Care and Emergency, Symbiosis University Hospital and Research Centre, Pune speaking on donor management

One Week Transplant Coordinators' Training Programme held in Chennai



(L to R) Dr. Sumana Navin (Course Director, MOHAN Foundation), Ms. Jiang Wenshi and Ms. Weinan Chen (China)



Dr. K. Sridhar, Director, Institute of Neuroscience, MGM Healthcare Pvt Ltd explaining Brain Stem Death

MOHAN Foundation successfully conducted a one-week Transplant Coordinators' Training Programme from 20th to 24th January 2020 at MOHAN Foundation, Chennai. This was the 67th training programme and the training was supported by Tata Trusts. There were a total of 24 delegates from different parts of the country - Tamil Nadu, Bihar, Uttar Pradesh, Kerala, Maharashtra, Haryana, Himachal Pradesh, and New Delhi. The training also had international representation (China) – faculty and observer. The faculty members included eminent physicians, surgeons, and senior transplant coordinators from the city. The MOHAN Foundation faculty comprised Dr. Sumana Navin, Course Director, Ms. Sujatha Suriyamoorthi, Manager-Information Systems, and Ms. Ann Alex, Programme Associate.



Mrs. Shaila Shroff, MOHAN Foundation presenting an appreciation certificate to Dr. Suresh Sankar, Nephrologist, VS Hospital & Frontier Lifeline Hospital



Participants during the role play



Ms. L. Sendhamarai Selvi, Renal Transplant Coordinator, Madras Medical Mission during her session on 'Recipient Coordination – Kidney'

There was an invited session on 'Overview of deceased organ donation and transplantation in China' by Ms. Jiang Wenshi, Intelligence Sharing for Life Science Research Institute. During her session, Ms. Wenshi spoke about the organ donation and procurement model in China and various training and awareness initiatives undertaken by the government to improve the organ donation rate.

The training programme concluded with a session on 'Role and responsibilities of Transplant Authority of Tamil Nadu (TRANSTAN)' by Dr. R. Kanthimathy, Member Secretary, TRANSTAN. She briefed the participants about the deceased donation programme in Tamil Nadu, state organ distribution system and state government guidelines/support in facilitating the programme. At the valedictory function, the participants received their completion certificates from Dr. R. Kanthimathy.

Training Programme



Dr. Gomathy Narasimhan, Sr. Consultant, HPB Surgery & Liver Transplantation, Dr. Rela Institute & Medical Centre explaining organ retrieval (liver).



Dr. R. Kanthimathy, Member Secretary, TRANSTAN (left) and Ms. Sujatha Suriyamoorthi, Manager-Information Systems, MOHAN Foundation (right) handing over the completion certificate to Mr. Alok Kumar Mishra, Apollomedics Hospital, Lucknow



Faculty and participants at the training

“ The whole course is a great journey to me through which I could learn a different perspective and culture. The most impressive session is the sharing from experienced coordinators. Through their stories, I could feel a big vision and strong sense of responsibility. It is LOVE why people come to do this and that drives the whole career keep developing here. Besides the great teaching sessions, I also enjoyed the interaction in the class. Everyone would share opinions and insights freely which helped us learn more from each other. The whole process is very well organized, not only for the topics but also the schedule. I cannot believe I could learn so many topics in a few days. Great thanks to MOHAN organization for giving me this opportunity to join this journey with you. It is also an opportunity for me to experience a different culture and know so many lovely Indian people, which becomes a valuable and unforgettable memory in my life.”



Ms. Weinan Chen
Trainer of Communication
China Organ Donation
Community

“ I attended the 'transplant coordinator training programme' from 20th to 24th January 2020 and gained a lot. Not just the knowledge of the topic but about various other things too, like how the programme is being run which is contributing to the society in a big way (as Mr Anupam Srivastava, from HR cell Apollo Delhi correctly said that "they are beautifully running the programme from a small area").

In my career, neither I ever planned nor I had an idea that such programmes are available. As said good things often happen unplanned, so was my volunteering for Donor Advocate as additional responsibility and hence this training later on.”



Dr. Sankalp Jha
Risk Manager and Donor Advocate
Indraprastha Apollo Hospital
New Delhi

Actor Rahul Bose joins hands with Edelweiss Tokio Life Insurance in its organ donation drive called #ZindagiUnlimited launched in collaboration with MOHAN Foundation



Actor Mr. Rahul Bose (third from right) with MOHAN Foundation team

A month-long drive was launched on 5th November 2019 by Edelweiss Tokio Life Insurance in collaboration with MOHAN Foundation (MF) focussing on debunking myths around organ donation in India and urging people to step up and take the pledge to become organ donors. At the launch event a Research report, 'Life After Life: State of Organ Donation in India' was unveiled by the dignitaries - Mr. Rashesh Shah (Chairman and CEO Edelweiss Group), Mr. Sumit Rai (MD & CEO Edelweiss Tokio Life Insurance), Mr. Runjan Panjwani (Executive Director Edelweiss Tokio Life Insurance), Mr. Rahul Bose (Actor), Dr. Sunil Shroff (Managing Trustee, MOHAN Foundation), and Dr S. K. Mathur (President, ZTCC Mumbai). A digital film with Rahul Bose titled #NoMoreWaiting was also launched and has hit more than 1 million views.

The research report was based on a two-week survey conducted across 12 major cities — Delhi, Lucknow, Jaipur, Mumbai, Ahmedabad, Indore, Chennai, Bangalore, Kochi, Kolkata, Patna, and Guwahati - and touched base with more than 1,500 respondents in the age group of 20-60 years. It brought to light some interesting trends, myths and beliefs that people have regarding organ donation. It showed that 80% of the respondents were aware of the concept of organ donation, but only 3% ended up actually taking the pledge due to lack of clarity on the process of how to donate. Edelweiss Tokio Life Insurance also received a GUINNESS WORLD RECORDS title for collecting the highest number of pledges for organ donation in a single day - 54,626 pledges on November 28, 2019.



(L to R) Mr. Sumit Rai, MD & CEO, Edelweiss Tokio Life Insurance, Mr. Rashesh Shah (Chairman & CEO, Edelweiss Group) & Dr. Vasanthi Ramesh (Director, NOTTO) receiving the GUINNESS WORLD RECORDS title

Organ Recipients and more than 100 Runners run the Tata Mumbai Marathon 2020 promoting Organ Donation

On 19th January 2020, more than 100 runners ran various categories at the Tata Mumbai Marathon 2020, including the Dream Run, 10 KM run and the Half Marathon (21KM), raising awareness about organ donation and in support of MOHAN Foundation's work.



Special Event



A few organ recipients, part of MOHAN Foundation's Organ Recipient Support Group called TRIOMPH (Transplant Recipients' Indian Organisation Meant to Provide Hope) joined the Dream Run, thereby sending a strong message across that Organ Recipients get to lead good lives once they get the life-saving organs through organ donation and transplantation. Rest of the runners ran in support of the cause. They all ran wearing MOHAN Foundation's T-shirts with the message #ProudOrganDonor

Ms. Jaya Jairam herself a Kidney Recipient and Project Manager of MOHAN Foundation, Mumbai motivated and inspired all recipients and others supporting the cause to come forward to form this unique group which included Senior Citizens, Liver Recipient Mr. Naresh Vaidya, Kidney recipients Mr. Kishore Suryawanshi (a Limca Book record holder) and Mr. Prakash Correa, and Miss. Shreya Siddanagowder, India's first Bilateral Upper Hand Transplant recipient.

Rangoli Competition to Promote Organ Donation held at Metro Station in Chennai



A sample of the creativity



Bird's-eye view of the competition



Dr. Alamelu and Mr. Simon Raj understanding the concept from a participant



Dr. K. Usha and Mr. Suresh judging the student category



Participant creating a rangoli design



Mr. Pravin Bihani honouring the Chief Guest Mrs. Lingaselvi, Hand Transplant recipient

MOHAN Foundation organised a Rangoli competition in association with Chennai Metro Rail Limited to promote the cause of organ donation on 8th February 2020. The venue was the Shenoy Nagar Metro Station, Chennai. This was the second such festival organised at the Metro in Chennai.

The theme of the Rangoli competition was organ donation and it was named அழியாத கோலங்கள் (Unerasable Kolams/Rangoli) with reference to how donated organs can continue living even after the donor's demise. Colourful, vibrant, innovative and beautiful Rangolis adorned the floor space of the station. The importance of blood donation, eye donation and organ donation were aesthetically and powerfully conveyed. A highly creative team depicted a real-time situation to communicate the importance of green corridor.

The chief guest for the occasion was Mrs. Lingaselvi, a double hand recipient from Chennai. She spoke about her journey – the surgery and recovery, and the way her life had changed positively after receiving the hand transplant. She also shared the experience of meeting the family of her donor in a felicitation ceremony in Kochi and being overwhelmed by their large heartedness. Mrs. Lingaselvi was felicitated by Mr. Pravin Bihani of Alstrut India Private Limited. Prizes were given away to the winners.

MOHAN Foundation wins at Grant Thornton SABERA



Ms. Pallavi Kumar, Executive Director (Delhi-NCR), MOHAN Foundation receiving the award

MOHAN Foundation's National Organ Donation Toll Free Helpline (supported by SBI Foundation and SBI DFHI Limited) won the Initiative Award (under 5 Crore budget) in the Swasthya Kalyan (Health and Well Being) Category and it also received the Not-for-profit of the year award (Below 5 Crore) under the Entity Award. Grant Thornton SABERA acknowledges and recognises Business & Social Enterprises along with individuals working responsibly. It honours and rewards corporates, NGOs and social heroes engaged in promoting sustainable development, and award categories are based on the United Nations Sustainable Development Goals 2030.

Dr. Bhanu Chandra receives Best Transplant Coordinator Award from NOTTO



Dr. Bhanu Chandra receiving the award from Sri Eatata Rajender, Health and Family Welfare Minister of Telangana

Dr. Bhanu Chandra working as Operations Manager at MOHAN Foundation, Hyderabad and posted at Osmania General Hospital, Hyderabad as Senior Transplant Coordinator through Jeevandan Telangana received the Best Transplant Coordinator Award for the year 2019-2020 from the National Organ & Tissue Transplant Organisation (NOTTO), Directorate General of Health Services, Ministry of Health and Family Welfare, Government of India on 30th November 2019 at Delhi. The award was handed over to Dr. Bhanu Chandra by the Health and Family Welfare Minister of Telangana, Sri Eatata Rajender on 10th December 2019 in Hyderabad.

Dr. Sunil Shroff awarded at Yugaantar, a National Youth Conference



In recognition and appreciation of his work, Dr. Sunil Shroff, Managing Trustee, MOHAN Foundation was awarded the "Hum Main Hain Hero" award at Yugaantar, The Maharaja Sayajirao University of Baroda's National Youth Conference, on 12th January 2020.

Jaya Jairam, Project Manager - MOHAN Foundation, Mumbai felicitated by Lions Clubs International at the hands of Mayor of Thane



Ms. Jaya Jairam felicitated by Lions Club International at the hands of Mayor of Thane, Mr. Naresh Mhaske

On 16th Feb 2020, Lions Clubs International (District 3231-A2) culminated "Thane Lions Fest 2020" with an award ceremony in which they felicitated a few select persons for their contribution to a social cause. Mayor of Thane, Mr. Naresh Mhaske was the Chief Guest of the event. Ms. Jaya Jairam was felicitated at the hands of the Mayor for her contribution to the cause of organ donation.

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Sd/-

Sunil Shroff

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Educate patients with hypertension/
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To spread awareness on
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Indication : For the treatment of mild to moderate hypertension. **Dosage and Administration** : The recommended adult oral dosage of Cilnidipine is 5-10 mg once daily. The dosage can be increased up to 20 mg, if needed. **Adverse Reactions** : Dizziness, Flushing, Headache, Hypotension, peripheral edema, Tachycardia, Palpitations, GI disturbances & increased micturition frequency. **Warnings and Precautions** : Hypotension, poor cardiac reserve, heart failure. Sudden withdrawal may exacerbate angina. Discontinue in patients who experience ischemic pain following administration. Pregnancy, lactation. **Contraindications** : Cilnidipine is contraindicated in patients with known hypersensitivity (e.g., anaphylaxis or angioedema) to Cilnidipine or any other component of this product.

Additional Information is available on request

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