

INDIAN TRANSPLANT NEWSLETTER

A quarterly publication from

MOHAN FOUNDATION

MULTI ORGAN HARVESTING AID NETWORK

Vol.17 Issue No.: 54

July 2018 - October 2018

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Editorial Desk**You Can 'Pledge to be an Organ Donor' using the Driving License in India**

Organ transplants cannot occur without the generosity of organ donors be it living or deceased donors. One can elect to be a donor after death by either carrying an organ donor card and keeping the near relatives informed or pledge through another instrument like the driving license. This method is popular and an important tool not only to spread the message, but also to ease the consent process when a person is pronounced dead. Countries such as USA, UK, Australia, Spain, Japan

and New Zealand have used this method very effectively. In some of these countries the driver donor registry becomes the first point of reference when a person is pronounced dead in a hospital before the relatives are approached for consent.

For the last 12 years, MOHAN has conducted innumerable campaigns to push this initiative forward. Way back in 2006-07 it did a drive and collected 5,000 signatures and forwarded it to the Ministry of Road Transport & Highways and on 20th September 2009 handed it over to the then transport commissioner at a public function (1). In 2010, it sent this as one of the many recommendations to the Rajya Sabha standing committee that was looking at the various inclusions in the new transplant law. Other NGOs like 'Gift Your Organ' from Bangalore have also pushed for this initiative and were using stickers on the driving license in Bangalore to denote that a person wished to donate his/her organs(2). They have apparently had 62,000 organ pledges on the driving license in Bangalore (3).

Ms. Bhavna Jagwani from MOHAN Foundation -Jaipur Citizen Forum in a personal interview last year with the Minister of Road Transport & Highways, Mr. Nitin Gadkari appealed for the organ donation clause to be included on the driving license and she was assured that this would be taken up soon and executed. Meanwhile the Ministry of Health officials and the National Organ & Tissue Transplant Organisation (NOTTO) too appealed to various ministries. All these efforts have at last culminated into this clause now being included in the Indian Driving License.

The Ministry of Road Transport & Highways has amended the Central Motor Vehicle Rules 1989 and on 20th March 2018 included the option of Organ and Tissue donation in the application (Form 2)as well as in the driving license - Form 6 & Form 7 (4).

Currently 997 RTOs in the country issue over 1.15 crore fresh or renewed driving licences every year. A rough calculation shows that on an average, 40 licenses are issued by each RTO on any working day. The challenge is likely to be to make the clause visible and have a mechanism for clarifying doubts.

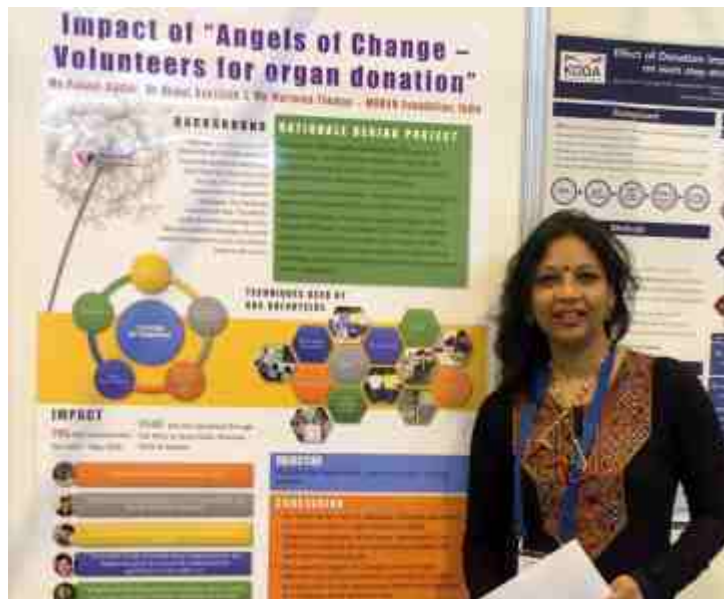
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MOHAN Foundation representation at TTS 2018 in Madrid



Ms. Pallavi Kumar with her poster on 'Impact of training volunteers for creating awareness on organ donation'

Dr Sunil Shroff (Managing Trustee) and Ms Pallavi Kumar (Executive Director NCR) represented MOHAN Foundation at the TTS 2018 – 27th International Congress of The Transplantation Society (TTS) at Madrid, Spain from June 30 - July 05, 2018. The theme of this year's conference was "Outcome Driven." In her Presidential Address, Dr Nancy Ascher spoke about the role of women in the field of transplantation.

TTS is a non-profit NGO providing global leadership in transplantation. Its core mission includes the development of the science and clinical practice, scientific communication, continuing education and guidance on ethical practices.

The congress consisting of post graduate courses, pre-congress workshops, oral sessions plenaries, poster presentations and campfire sessions saw the representation of close to 3,000 transplant professionals from around the world. Lectures covered an array of topics, including the latest developments in transplantation science, clinical practices and improving patient outcomes. The first new edition of the Declaration of Istanbul on Organ Trafficking and Transplant Tourism was also presented (a write-up is available on pages 4 – 6). MOHAN Foundation is one of the Endorsing Organisations of the Declaration of Istanbul.

Ms Pallavi Kumar made an oral presentation on, "Experiences & Challenges in an NGO run Helpline" under the 'Innovation in Transplant Education' section. She also presented a poster on, "Impact of training volunteers for creating awareness on organ donation" showcasing the Foundation's Angels of Change initiative.



Dr. Sunil Shroff presenting at the Campfire Session on Ethical Challenges in Donation and Transplantation

Dr Sunil Shroff made two presentations under the campfire session titled, "Ethical Challenges in Donation and Transplantation" -

- Ethical Dilemmas in Deceased Organ Donation and Allocation – an emerging challenge in India
- Unique Challenges in the Deceased Donation Program in India

4th National Convention & Scientific Seminar on Organ Transplantation held in Dhaka, Bangladesh



Faculty at the seminar in Dhaka - (From left to right) Dr. Kapil Zirpe, Dr. Sumana Navin, Dr. Sunil Shroff, Dr. Harun Ur Rashid, Dr. Jae Myeong Lee, and Dr. Nizamuddin Chowdhury

The 4th National Convention & Scientific Seminar on Organ Transplantation was held from 16th to 18th September 2018 in Dhaka, Bangladesh. The meeting was organised by the Society of Organ Transplantation (SOT), Bangladesh in collaboration with the Asian Society of Transplantation and MOHAN Foundation at the Bangabandhu Sheikh Mujib Medical University, Dhaka Medical College and Kidney Foundation, Dhaka. Dr. Harun Ur Rashid, President, SOT invited Dr. Sunil Shroff, Mrs. Lalitha Raghuram, and Dr. Sumana Navin from MOHAN Foundation as faculty. The international faculty also included Dr. Jae Myeong Lee from South Korea, Dr. Kapil Zirpe, Dr. Subhal Dixit and Dr. Vivek Kute from India.

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A liver transplant 27 hours after retrieval - thanks to OrganOx Metra machine

In what is perhaps the first of its kind, a cadaver liver travelled by road from Chennai to Coimbatore and was transplanted almost 27 hours after it was harvested. On Sunday 28th October 2018 when a 56-year-old trauma patient's family came forward to donate his liver, a few centres in Chennai rejected the organ because of its sub-optimal quality, but a patient in Coimbatore agreed to take it. Dr. S. Swaminathan, liver transplant surgeon at PSG Hospitals, Coimbatore, said he held discussions with his patient, a 65-year-old woman, who had suffered liver cirrhosis. The organ, which was harvested at 11 a.m. on Sunday at Vijaya Hospital and connected to the perfusion machine (OrganOx) in the evening, left Chennai at 9.30 p.m. and reached Coimbatore's PSG Hospitals at 9 a.m. on Monday. By 2.15 p.m., the liver got reperfused in the recipient.

The machine was transported by ambulance. "It is a logistical nightmare, but when the liver is on the machine we can preserve it for a longer time," Dr. Swaminathan added. Subith Kumar, Chief Executive Officer of Duraent Life sciences, which transported the OrganOx Metra machine and the liver, said there were several firsts to this transplant. After harvesting the liver, it was transported in ice to RPS Hospital in Kolathur for cannulation. From there, it was transported by ambulance to Coimbatore about 500 km away. The vehicle made four stops in 10 hours to evaluate the various parameters of liver function. "The liver was on the machine for more than 17 hours, a record for India," he said.

Woman delivers baby after getting uterine transplant from mother in Pune

In Pune, a baby was born from the same uterus which carried her mother. On 18th May 2017, the baby's mother, Meenakshi Walan, got a uterus transplant from her mother as her uterus was damaged and couldn't conceive a baby. 17 months later, after getting her mother's uterus, Meenakshi delivered a baby girl at the Galaxy Care Hospital in Pune.

Meenakshi, 27 years, was kept under observation for a few months after her transplant. She was sent back home to Gujarat once her health showed improvement. When she experienced her first menstrual cycle, she went back to Pune. In March 2018, the embryo was transferred to her new uterus. And after 31 weeks and 5 days (over 7 months), Meenakshi prematurely underwent a caesarean section.

The surgeon behind the miracle, Dr. Shailesh Puntambekar, said that history had been created. This is the twelfth baby in the world to be born through a uterus transplant. Nine such babies were born in Sweden, two in the United States, and now this was the first one in all of Asia.

Jaipur Monuments lit with green light to support the cause of organ donation



Statue Circle lit up in green

On the occasion of world organ donation day 13th August 2018, important archeological buildings of Jaipur such as Hawa Mahal, Albert Hall, Amber Fort, and Statue Circle were illuminated in green at night. The Department of Tourism and Art and Culture gave its consent for the monuments to be lit in green to spread awareness about the noble cause of organ donation among the people.



Hawa Mahal lit up in green

...Editorial continued

Otherwise routinely the clerk may just mark 'No' in front of the clause without even informing the potential candidate seeking the license. The driver donor registry can become functional in India once sufficient pledges have been received.

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The **DECLARATION** of **ISTANBUL** on **ORGAN TRAFFICKING** and **TRANSPLANT TOURISM**



On July 1, 2018 at the 27th International Congress of TTS (The Transplantation Society) in Madrid (Spain), the first new edition of the Declaration of Istanbul on Organ Trafficking and Transplant Tourism was presented. This marked 10 years of the Declaration of Istanbul (DoI), a seminal document that has helped to guide ethical practice in organ donation and transplantation around the world. The revisions made in this 2018 Edition are intended to ensure that the DoI remains a valuable source of ethical guidance for health professionals and policy makers during the next decade in the face of persisting and emerging challenges in organ trafficking and transplant tourism around the world.

The Declaration was originally published in 2008, following a landmark summit convened by The Transplantation Society (TTS) and the International Society of Nephrology (ISN) in Turkey in response to growing concerns about international trafficking in human organs.

Background

As a consequence of the widespread shortage of organs and the increasing ease of Internet communication, organ trafficking and transplant tourism have become global problems accounting for an estimated 10% of organ transplants that are performed annually around the world. Organ trafficking, transplant tourism and transplant commercialism threaten to undermine the nobility and legacy of transplantation worldwide because of the reality associated with these practices – the vulnerable in resource poor countries (such as the illiterate and impoverished, undocumented immigrants, prisoners, and political or economic refugees) are exploited for their organs as a major source of organs for the rich patient-tourists who are prepared to travel and can afford to purchase organs.

In 2004, the World Health Assembly urged member states to take measures to protect the poor and vulnerable from transplant tourism and to address the wider problem of international trafficking of human organs and tissues.

In December 2006, concerned by the ongoing problems of international organ trafficking and the global shortage of organs for transplantation, representatives from The Transplantation Society met with representatives of the International Society of Nephrology and conceived the idea of developing a formal Declaration that would serve to inspire and unite all those engaged in combating unethical practices in organ transplantation. A Steering Committee was convened in Dubai and Ankara Turkey during 2007 which laid the foundations for the 2008 Istanbul Summit. The Summit goals were to assemble a final Declaration that would define organ trafficking, transplant tourism and commercialism, and achieve consensus regarding principles of practice and recommend alternatives to address the shortage of organs.

The Istanbul Summit

These unethical practices in transplantation were the subject of the Summit convened in Istanbul from 30 April to 1 May 2008 by The Transplantation Society (TTS) and the International Society of Nephrology (ISN). The result of these deliberations was the Istanbul Declaration on Organ Trafficking and Transplant Tourism.

More than 150 representatives of scientific and medical bodies from 78 countries around the world, including government officials, social scientists and ethicists assembled in Istanbul, Turkey to work on the drafting of the Declaration of Istanbul. Working groups were assigned to develop the various components of the Declaration and the results of their meetings were presented at plenary sessions for approval. The Declaration of Istanbul was derived from the consensus reached by the participants at the Summit in those plenary sessions.

It established definitions of practices and principles to guide policy makers and health professionals working in organ donation and transplantation. Since 2008, more than 135 professional societies have formally endorsed the Declaration.

This Declaration builds on the principles of the Universal Declaration of Human Rights. The broad representation at the Istanbul Summit reflects the importance of international collaboration and global consensus to improve donation and transplantation practices. The Declaration was submitted to relevant professional organizations and to the health authorities of all countries for consideration. The Declaration believes that the legacy of transplantation must not be the impoverished victims of organ trafficking and transplant tourism but rather a celebration of the gift of health by one individual to another.



Principles

The key ethical principles of the Declaration (as updated in 2018) and fundamental requirements for organ donation and transplantation to guide transplantation practices are as follows:

1. Governments should develop and implement ethically and clinically sound programs for the prevention and treatment of organ failure, consistent with meeting the overall healthcare needs of their populations
2. The optimal care of organ donors and transplant recipients should be a primary goal of transplant policies and programs.
3. Trafficking in human organs and trafficking in persons for the purpose of organ removal should be prohibited and criminalized.
4. Organ donation should be a financially neutral act.
5. Each country or jurisdiction should develop and implement legislation and regulations to govern the recovery of organs from deceased and living donors and the practice of transplantation, consistent with international standards.
6. Designated authorities in each jurisdiction should oversee and be accountable for organ donation, allocation and transplantation practices to ensure standardization, traceability, transparency, quality, safety, fairness and public trust.
7. All residents of a country should have equitable access to donation and transplant services and to organs procured from deceased donors.
8. Organs for transplantation should be equitably allocated within countries or jurisdictions, in conformity with objective, non-discriminatory, externally justified and transparent rules, guided by clinical criteria and ethical norms.
9. Health professionals and healthcare institutions should assist in preventing and addressing organ trafficking, trafficking in persons for the purpose of organ removal, and transplant tourism.
10. Governments and health professionals should implement strategies to discourage and prevent the residents of their country from engaging in transplant tourism.
11. Countries should strive to achieve self-sufficiency in organ donation and transplantation.

Definitions

The practices that the Declaration seeks to eradicate have specified meanings in the context of the Declaration of Istanbul. Newer definitions were added in the 2018 edition.

- Organ trafficking consists of any of the following activities:
 - (a) Removing organs from living or deceased donors without valid consent or authorization or in exchange for financial gain or comparable advantage to the donor and/or a third person;

- (b) Any transportation, manipulation, transplantation or other use of such organs;
- (c) Offering any undue advantage to, or requesting the same by, a healthcare professional, public official, or employee of a private sector entity to facilitate or perform such removal or use;
- (d) Soliciting or recruiting donors or recipients, where carried out for financial gain or comparable advantage; or
- (e) Attempting to commit, or aiding or abetting the commission of, any of these acts.

- Trafficking in persons for the purpose of organ removal is the recruitment, transportation, transfer, harboring, or receipt of persons, by means of the threat or use of force or other forms of coercion, of abduction, of fraud, of deception, of the abuse of power or of a position of vulnerability, or of the giving or receiving of payments or benefits to achieve the consent of a person having control over another person, for the purpose of the removal of organs.

In the context of this Declaration, the term resident denotes a person who makes their life within a country, whether or not as a citizen; the term non-resident denotes all persons who are not residents, including those who travel to, and then reside temporarily within, a country for the purpose of obtaining a transplant.

- Travel for transplantation is the movement of persons across jurisdictional borders for transplantation purposes. Travel for transplantation becomes transplant tourism, and thus unethical, if it involves trafficking in persons for the purpose of organ removal or trafficking in human organs, or if the resources (organs, professionals and transplant centers) devoted to providing transplants to non-resident patients undermine the country's ability to provide transplant services for its own population.

- Self-sufficiency in organ donation and transplantation means meeting the transplant needs of a country by use of donation and transplant services provided within the country and organs donated by its residents, or by equitably sharing resources with other countries or jurisdictions.

- Financial neutrality in organ donation means that donor and their families neither lose nor gain financially as a result of donation.

Proposals

The document provides practical suggestions for meeting the ethical goals of the Declaration and clarification of important issues such as reimbursement of donation costs.

To respond to the need to increase deceased donation

1. Governments, in collaboration with healthcare institutions, professionals, and nongovernmental organizations should take appropriate actions to increase deceased organ donation. Measures should be taken to remove obstacles and disincentives to deceased organ donation.
2. In countries without established deceased organ donation or transplantation, national legislation should be enacted that would initiate deceased organ donation and create transplantation infrastructure, so as to fulfill each country's deceased donor potential.
3. In all countries in which deceased organ donation has been initiated, the therapeutic potential of deceased organ donation and transplantation should be maximized.
4. Countries with well-established deceased donor transplant programs are encouraged to share information, expertise, and technology with countries seeking to improve their organ donation efforts.

To ensure the protection and safety of living donors and appropriate recognition for their heroic act while combating transplant tourism, organ trafficking, and transplant commercialism

1. The act of donation should be regarded as heroic and honored as such by representatives of the government and civil society organizations.
2. The determination of the medical and psychosocial suitability of the living donor should be guided by the recommendations of the Amsterdam and Vancouver Forums.
 - a. Mechanisms for informed consent should incorporate provisions for evaluating the donor's understanding, including assessment of the psychological impact of the process;
 - b. All donors should undergo psychosocial evaluation by mental health professionals during screening.
3. The care of organ donors, including those who have been victims of organ trafficking, transplant commercialism, and transplant tourism, is a critical responsibility of all jurisdictions that sanctioned organ transplants using such practices.
4. Systems and structures should ensure standardization, transparency, and accountability of support for donation.
 - a. Mechanisms for transparency of process and follow-up should be established;
 - b. Informed consent should be obtained both for donation and for follow-up processes.
5. Provision of care includes medical and psychosocial care at the time of donation and for any short- and long-term consequences related to organ donation.

- a. In jurisdictions and countries that lack universal health insurance, the provision of disability, life, and health insurance related to the donation event is a necessary requirement in providing care for the donor;
 - b. In those jurisdictions that have universal health insurance, governmental services should ensure donors have access to appropriate medical care related to the donation event;
 - c. Health and/or life insurance coverage and employment opportunities of persons who donate organs should not be compromised;
 - d. All donors should be offered psychosocial services as a standard component of follow-up;
 - e. In the event of organ failure in the donor, the donor should receive:
 - i. Supportive medical care, including dialysis for those with renal failure, and
 - ii. Priority for access to transplantation, integrated into existing allocation rules as they apply to either living or deceased organ transplantation.
6. Comprehensive reimbursement of the actual, documented costs of donating an organ does not constitute a payment for an organ but is rather part of the legitimate costs of treating the recipient.
 - a. Such cost-reimbursement would usually be made by the party responsible for the costs of treating the transplant recipient (such as a government health department or a health insurer);
 - b. Relevant costs and expenses should be calculated and administered using transparent methodology, consistent with national norms;
 - c. Reimbursement of approved costs should be made directly to the party supplying the service (such as to the hospital that provided the donor's medical care);
 - d. Reimbursement of the donor's lost income and out-of-pocket expenses should be administered by the agency handling the transplant rather than paid directly from the recipient to the donor.
 7. Legitimate expenses that may be reimbursed when documented include:
 - a. the cost of any medical and psychological evaluations of potential living donors who are excluded from donation (e.g., because of medical or immunologic issues discovered during the evaluation process);
 - b. costs incurred in arranging and effecting the preoperative, perioperative, and postoperative phases of the donation process (e.g., long-distance telephone calls, travel, accommodation, and subsistence expenses);
 - c. medical expenses incurred for post discharge care of the donor;
 - d. Lost income in relation to donation (consistent with national norms).

Ms. Pallavi Kumar
Executive Director
MOHAN Foundation, Delhi - NCR

The Importance of Being Truthful



Ms. Jigisha Yadav
Transplant Coordinator
MOHAN Foundation, Mumbai

Mr. Ashok Bhogle, a 48-year-old male patient was admitted at Apollo Hospital, Navi Mumbai, on 10th September 2018 with Intracranial Bleed.

On 10th September 2018, the ICU Head at Apollo Hospitals Navi Mumbai informed me (since I am MOHAN Foundation's Transplant Coordinator deputed to the hospital) about a potential brain dead donor in the neuro critical care unit.

A few moments prior, Mrs. Veena Ashok Bhogle had been given primary information by the ICU doctor that the patient was not responding to any stimuli and that they were suspecting that the brain functions had ceased. Even in those grief-stricken moments when she seemed to be gradually processing it all, she was anxious to know "Is there anything else that can be done now?"

Dr. Tushar Parmar, the ICU doctor, guided her that she could consider donating the organs of her husband for the larger cause of helping patients in need of organs. She requested more information on this. The doctor informed her that MOHAN Foundation's counsellor would shortly get in touch with her.

At 1 pm I spoke to Mrs. Bhogle and the patient's sister-in-law, in the critical care counselling room, in the presence of Apollo's own Transplant Coordinators, Mr. Santosh Sorate and Mr. Prakash Saindane. I softly asked Mrs. Bhogle if she had understood the condition that her husband was in. She replied saying that she understood that her husband was in an irreversible condition as explained to her by Dr. Parmar. She further added that she wanted to explore the possibility of organ donation because she felt that by donating her organs her husband would be alive in many people who are desperately waiting for an organ. She then requested for more information about the process of organ donation.

I then explained the process in great depth and also cleared her doubts such as how much time the whole process would take, who would the organs go to, would the recipient details be shared with the family, what all organs could be harvested and would the procedure cause any mutilation to the body. Having understood all that, Mrs. Bhogle was ready to go ahead.

Meanwhile Dr. Shailesh Kalamkar (Neurosurgeon) initiated appropriate monitoring and management of the patient at the ICU as per standard guidelines for a brain stem dead organ donor. Dr. Gunadhar Padhi (Intensivist) along with Dr. Shailesh Kalamkar did the first apnoea testing at 3.20 pm and the findings were recorded in the case file.

At 5.30 pm I received a call from the Mrs. Bhogle saying that she wished to meet me once again. The meeting took place in the counselling room but this time Mrs. Bhogle was accompanied by another gentleman whom she introduced as her 'Mama' (Uncle).

She informed me that while she was convinced about donating her husband's organs but she wanted that the liver must be given to the accompanying gentleman, who she said, was a close family friend cum neighbour, whom she knew since 15 years. In fact, she added that she will consent to the donation only if the liver is given to the neighbour.

Along with the other Medical Social Workers I explained to her and the neighbour about the allocation process being transparently laid out in the law. They were assured that all rights of organ allocation lie only with the state allocation nodal agency i.e. ZTCC (Zonal Transplant Co-ordination Centre). As an example, the story of Shri Vilasrao Deshmukh (ex-CM of Maharashtra) was shared that when he was in need of liver and kidney, he still had to wait for his turn on the waiting list and in spite of his huge political clout, organs were not allocated to him out of turn and that organs are allocated strictly as per the waiting list only.

The neighbour started grumbling that it was unfair that in spite of him being a close family friend and in spite of the patient's wife wanting to give him a liver, he was unable to get it. The hospital's Medical Social Worker reiterated saying that the rules apply to all and that if the family decided not to go ahead with the donation, their decision will be respectfully accepted.

Mrs. Bhogle was told to take her time and make up her mind. She seemed satisfied with all the replies and immediately gave her consent to go ahead with the donation. The formal consent was taken and subsequently the transplant teams were intimated. Second Apnoea test was concluded at 10.50 pm and the findings were recorded in the brain stem death certification form (Form No. 10) with the signatures of the Board of team Medical Experts namely, Dr. Prasad Muglikar, the Medical Superintendent in-charge of the hospital, Dr. Vaishali Lokhande, authorised specialist, Dr. Sunil Kutty, treating doctor and Dr. Suvadeep Sen, Neurologist.

On 12th September 2018, at 2am, the donor was shifted to the operation theatre for retrieval of organs. Finally, the donor's body was wheeled into the ICU at 10 am for the final packing. The clothes in which the body was to be packed were given to the nursing staff of the ICU. All measures were taken to ensure that the donor's family did not face any procedural delays in the release of the body. All the documents were handed over to the donor's sister in law. The body was then shifted to the mortuary and from there it was respectfully handed over to the relatives at 1 pm.

The heart, liver, two kidneys, two lungs, skin and corneas were donated. More than 8 lives were saved.

Dr. Avnish Seth - Leading from the front



Dr. Avnish Seth, MD, DM



Actor Priyanka Chopra supporting organ donation



The Delhi Daredevils IPL team supporting organ donation

Dr. Avnish Seth, MD, DM is Director, Gastroenterology & Hepatobiliary Sciences and Director, Fortis Organ Retrieval & Transplant (FORT) at Fortis Memorial Research Institute (FMRI), Gurugram. The quintessential 'Officer and a Gentleman' has been a driving force of the organ donation movement in India. He shared his experiences in an email interview with Dr. Sumana Navin.

Your professional journey started in the Army Medical Corps – how was that experience?

It has been my privilege to serve in the Army Medical Corps for 27 years. Wearing a uniform is a very special feeling. The camaraderie and brotherhood is unmatched and so is the professionalism. I got the opportunity to teach Medicine at my Alma Mater i.e. Armed Forces Medical College Pune, pursue Gastroenterology at PGIMER Chandigarh and also a fellowship in Liver Transplantation at UK. We started the first successful Deceased Donor Liver Transplantation program in North India at Army Hospital Research & Referral, New Delhi in 2007. It was an honor to receive the Vishisht Seva Medal from the President of India in 2008.

What was the genesis of the Armed Forces Organ Retrieval & Transplantation Authority (AORTA)?

It was my stay in England for 6 months that made me realize that in India one went through school, college, MBBS, MD and DM without even a mention of brain death and deceased organ donation! On our return, everyone told us that organ donation does not happen in India and one should focus on living donor liver transplantation. We decided to give it a try and I asked my MD student to look for brain death prospectively as a thesis protocol. We got the paperwork in order and within 15 days we had our first multi-organ donation! I remember the wave of awe and positivity that swept through the hospital but we were not surprised. One had realized that the problem was not that the people of India were averse to organ donation but that we had not bothered to have systems in place. Buoyed by the success, I sought an appointment with the Director General of Armed Forces Medical Services and made a presentation. All the senior management was very supportive and the Armed Forces Organ Retrieval & Transplantation Authority (AORTA) was born.

Why did you move to the private sector and how did Fortis Organ Retrieval & Transplant (FORT) come about?

Unfortunately, the Armed Forces could not keep our team together at Army Hospital R&R despite us doing 30 deceased donor liver transplants in two years. I took premature retirement in 2009 and joined BL Kapur Superspeciality Hospital where we were able to start a successful deceased donation program. In 2012 Fortis Healthcare Limited, which has the largest chain of hospitals in the country, accepted my proposal to set up Fortis Organ Retrieval & Transplant (FORT) and I joined Fortis Memorial Research Institute (FMRI) at Gurugram.

What was the Green Corridor drill that FORT initiated?

In August 2014 with the help of police officials from Delhi and Gurugram we carried out the first mock drill on establishing a green corridor for transportation of heart in North India. Within 5 months, on 2nd January 2015 we were able to successfully transport a heart from FMRI Gurugram to Fortis Escorts at New Delhi, a distance of 32 Km in 29 minutes! The police have been very cooperative and established as many as 44 Green Corridors in 2017 in the NCR at short notice.

You have been one of the driving forces of the deceased donation program in the Fortis group of hospitals. What has been the impact?

We focused on the 18 large Fortis hospitals that carry out organ transplantation, made an SOP on diagnosis of brain death and organ donation and held workshops. It is important to remember that organ donation does not happen on its own. Someone has to push the program constantly. As of date we have had 83 organ donors in 11 of our major hospitals across the country leading to retrieval and transplantation of 236 organs (139 kidneys, 66 livers, 28 hearts, 2 lungs and 1 pancreas). We have also established a Nursing driven process where relatives are counseled for Cornea Donation after each death in hospital.

The NDTV-Fortis campaign to promote organ donation has been garnering a lot of interest over the past few years. What are some of the significant achievements of the campaign?

At Fortis Healthcare organ donation is a priority. The visiting card of every Fortisian carries a message to promote organ donation. The Fortis-NDTV 'More To Give' campaign is in its season-III this year. We have had brand ambassadors like actors Irrfan Khan, Swara Bhaskar, Rajkumar Rao, and Former Indian Hockey Captain Sandeep Singh over the last three years. Our short film to promote organ donation won the Dadasaheb Phalke award in 2017 and was viewed by over 10 million people on Facebook. Our simultaneous Walkathon, covered live on NDTV, has expanded from 6 cities to 12 this year.

We have been able to garner over 100,000 pledges so far. More To Give campaign was awarded the best CSR initiative in 2017. Does all this convert into more donations? The effect of what we do today will be seen over decades not years as it takes a generation to change the mindset of the nation. For me, the fact that six of our hospitals saw their first organ donation during the campaign is very significant.



NDTV - Fortis 'More to Give' Campaign

Why do you think collaboration in training initiatives for organ donation and transplantation is important?

Organ donation is all about teamwork. We have to constantly support each other and not be afraid to learn. Spain is the leader in the field of organ donation and for the last five years we have invited experts from there to participate in national level meetings on organ donation hosted by us. The FORT- MOHAN Foundation partnership has grown stronger over the years and we have been conducting an annual training program on Transplant Coordination for the last five years, more recently under the aegis of NOTTO.

You have 'walked the talk' when it comes to organ donation...

We had the misfortune of losing my mother-in-law, Smt. Uma Chopra in 2014. Having worked in organ donation for over a decade I experienced first-hand the difficulties in the process. A large tertiary care hospital in South Delhi had no approvals for certification of brain death. My Father-in-law found it difficult to accept the concept of brain death as the heart was still beating and we had to show him a flat EEG for him to accept the loss.

We realized the importance of involving the younger generation as it was my daughter who convinced her Nana (grandfather) to donate organs. Today we are all happy that she is alive in five people! The other day, after one of my talks at NOTTO, a young lady came up to me and said 'Sir, I just saw your presentation. Your mother's liver is inside me!' The sensation I felt when I shook her by the hand was overwhelming and cannot be described in words.

Your team has a first to its name in transplants in India - Stool transplant.

Yes, we performed the first stool transplant in the country on 14th November 2014 at FMRI and published the same. The research projects on stool transplant have expanded from Ulcerative Colitis to Irritable Bowel syndrome, Alcoholic Hepatitis, Metabolic syndrome and Parkinson's.

What are the challenges and what is the way forward for the deceased organ donation programme in India?

Efforts at increasing organ donation have to focus simultaneously on legislation, increasing awareness and establishing best practices on the subject in all hospitals. Only 16 out of 26 states and Union Territories have adopted the amended Transplantation of Human Organs and Tissues Act of 2011. Prominent states like Punjab and West Bengal have virtually no organ donation. Organ donation cannot be viewed in isolation. It is a part of delivering quality health care. The Government needs to spend more on health, have better trauma care services, better critical care, more ventilators and more trained staff.

Other than being an ardent advocate of organ donation, what is your passion?

Cricket! I had the rare privilege of playing 20 Ranji Trophy Cricket matches from 1982 to 1986. Rubbing shoulders against the World Cup winning team members of 1983 was special. Scoring three centuries against them is a great memory!

FORM - IV

Place of Publication: Chennai
 Periodicity of its Publication: Quarterly
 Printer's Name: Vishal Goel
 Nationality: Indian
 Address: Identity, 59A, Montieth Road, Egmore, Chennai 8
 Publisher's Name: Sunil Shroff
 Nationality: Indian
 Address: MOHAN Foundation, 267 Kilpauk Garden Road, Chennai 600010
 Editor's Name: Sunil Shroff
 Nationality: Indian
 Address: MOHAN Foundation, 267 Kilpauk Garden Road, Chennai 600010
 I, Sunil Shroff, hereby declare that the particulars given above are true to the best of my knowledge and belief.
 Sd/-
 Sunil Shroff
 Date: 31 October 2018
 Signature of Publisher

3rd AORTA-MOHAN Foundation training on TRANSPLANT COORDINATION under the aegis of NOTTO supported by Office of DGMS (Army) IHQ of MoD (Army)



Lt Gen Sanjiv Chopra DGHS, Army & Chairman AORTA giving the inaugural address



Lt Col Sandhya V Nair, Transplant Coordinator, Army R & R Hospital demonstrating the packing of organs



Lt General UK Sharma (Commandant, Army Hospital R&R) & Dr Sumana Navin, Course Director, MOHAN Foundation giving away the completion certificate to a participant



Participants and Faculty at 3rd AORTA-MOHAN Transplant Coordination Workshop at Army R&R Hospital

MOHAN Foundation in partnership with AORTA (Army Organ Retrieval & Transplant Authority) under the aegis of NOTTO (National Organ & Tissue Transplant Organisation) supported by Office of DGMS (Army) IHQ of MoD (Army) successfully completed the training on 'TRANSPLANT COORDINATION' from August 7-11, 2018 held at Army Hospital (Research and Referral) Delhi Cantt, New Delhi. This was the third training held in partnership with AORTA and was conducted under the guidance of Col P.K Sharma (Director, AORTA). The transplant coordinators training programme started with an inaugural function where the Chief Guest was Lt Gen Sanjiv Chopra, Director General of Health Services (Army). At the valedictory function, Lt Gen U.K Sharma, Commandant, Army Hospital (R&R) gave away completion certificates to 41 delegates who successfully completed the course. Lt Col Sandhya V Nair, Transplant Coordinator, Army Hospital (R&R) coordinated the training schedule with the MOHAN Foundation team. This training was supported by the Tata Trusts and Army Medical Corps.

One Week Transplant Coordinators' Training Programme held in Ahmedabad



Dr. Vasanthi Ramesh (left), Director, NOTTO at the Transplant Coordinators' Training Programme



Mr. Nikhil Vyas, Senior Manager - Clinical Operations, CIMS Hospital, Ahmedabad taking a session on living donation and transplantation



Dignitaries at the inaugural function



Faculty from MOHAN Foundation, Zydus Hospitals and ZOTTO Mumbai

Under the aegis of National Organ & Tissue Transplant Organisation (NOTTO), Directorate General of Health Services, Ministry of Health and Family Welfare, Government of India and ROTTO-SOTTO Mumbai, MOHAN Foundation conducted a one-week Transplant Coordinators' Training Programme from 25th to 29th September 2018 at Zydus Hospitals, Ahmedabad. There were 33 participants from Gujarat, Maharashtra, Madhya Pradesh, Karnataka, Kerala, Rajasthan, Assam and Manipur. This was the 56th training programme conducted by MOHAN Foundation and the 22nd in partnership with NOTTO. The training programme was supported by the Tata Trusts.

At the inauguration, Mr. Pankaj Patel, Founder of Zydus Hospitals, spoke about the importance of values and ethics in the work that transplant coordinators undertake. Dr. M. M. Prabhakar, Additional Director of Medical Education, Government of Gujarat, Dr. Sajan Nair, CEO, Zydus Hospitals and Dr. Biswarup Pal, Anaesthesiologist - Liver Transplant, Zydus Hospitals, and Ms. Bhavna Chhabaria, CEO, Shatayu were also present. Dr. Vasanthi Ramesh, Director, NOTTO kick-started the training with a lecture on the role and activities of NOTTO and the National Organ Transplant Programme.



Faculty and participants at the training

On the final day, Mrs. Sujata Ashtekar, Consultant, ROTTO-SOTTO, KEM, Mumbai made a presentation on the role, activities, and future plans of ROTTO. She said that they hoped to work closely with the Government of Gujarat. At the valedictory function, Dr. Sajan Nair and Dr. Sunil Shroff congratulated the participants and presented the completion certificates to them.

One Week Transplant Coordinators' Training Programme held in Madurai

For the first time in Madurai a one-week Transplant Coordinators' Training Programme was conducted from 8th to 12th October 2018 by MOHAN Foundation. This training was conducted under the aegis of National Organ & Tissue Transplant Organisation (NOTTO), Directorate General of Health Services, Ministry of Health and Family Welfare, Government of India and Transplant Authority of Tamil Nadu (TRANSTAN). There were 40 participants from Tamil Nadu, Maharashtra, Karnataka, Kerala, Bihar and Puducherry. This was the 57th training programme conducted by MOHAN Foundation and the 23rd in partnership with NOTTO. The training programme was supported by the Tata Trusts.



Participants listing out the procedures, legal formalities and role of a transplant coordinator involved in living donor transplants

The training programme started with an inaugural function. Dr. D. Maruthupandian, Dean, Madurai Medical College and Govt. Rajaji Hospital, Madurai, Dr. S. Shanmugasundaram, Medical Superintendent, Govt. Rajaji Hospital, Madurai, Mrs. Lalitha Raghuram, Country Director, MOHAN Foundation and Mr. K. Raghuram, graced the inaugural ceremony. During the chief guest address, Dr. D. Maruthupandian, Dean, Madurai Medical College and Govt. Rajaji Hospital, Madurai spoke about the tremendous work done in the state of Tamil Nadu in the field of organ donation and transplantation.



Mr. G. Mukesh, Transplant Coordinator, Velammal Medical College Hospital & Research Institute addressing the participants on the role of a recipient coordinator in liver transplantation

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MOHAN Foundation participates in the 2nd Year of Mini Fellowship in Organ Donation at Gift of Life Institute, Philadelphia, USA

Ms Pallavi Kumar, Executive Director (MF) and Ms Arati Gokhale, Convenor, ZTCC (Zonal Transplant Coordination Committee), Pune underwent Gift of Life Institute's (GOLI) Mini Fellowship in Organ Donation from October 15-26, 2018 in USA. This fellowship was facilitated under the auspices of the International Cooperation Agreement signed between Gift of Life Institute, Philadelphia and MOHAN Foundation in 2015. One of the objectives of the agreement was facilitating the enhancement of the deceased donation and transplantation program in India through education and training of donation and transplantation professionals in the country. The Mini Fellowship was sponsored through an educational grant from MOHAN, USA, Inc. which is a 501(c) (3) registered non-profit organization that was formed to increase awareness about organ shortage and promote transparency and ethical organ transplantation in India and the rest of the world (www.mohanusa.org)

Gift of Life Donor Program, Philadelphia is the largest non-profit Organ Procurement Organization (OPO) in USA that serves eastern Pennsylvania, southern New Jersey and Delaware. It facilitated 565 organ donations in 2017 that resulted in 1,546 transplants (50 donors per million population) – the highest volume in the U.S.

The Mini Fellowship comprised didactic sessions, observational learning, workshops and special events.

Didactic Sessions

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 allocation policies. All these aspects were covered by the experts during the following didactic sessions.

- History of organ donation in US and the Gift of Life Donor Program – Overview (along with a tour)
- Family Communication Models
- Transplant Information Center and Organ Allocation
- Family Support Services
- Donation and Transplant Analytics (DATA)
- Transplant Pregnancy Registry International

Two-Day Workshop on Family Empowerment through Effective Advocacy: Averting and Overcoming Obstacles to Donation

Pallavi and Arati attended a two-day Workshop on Dual Advocacy by Patti Mulvania at the Gift of Life Institute. The workshop covered the following topics:

- The intersection between Donation, Culture and Religion
- Timely and Goal Oriented FDCs: Triggers and Goals



Mr. Howard M. Nathan, CEO and President, Gift of Life Donor Program presenting the mini fellowship completion certificate to Ms. Pallavi Kumar

- Self-Care and Maintaining Professional Boundaries
- Managing Intense Emotions
 - Before the Donation Conversation: Setting it Up to Go Well
 - When a Child Dies – The Unique impact of Pediatric loss on Hospital Staff and Donation Professionals
- Strategy and Skill Building: From Strategy to Results

The workshop consisted of many individual and group exercises and role plays that offered the participants an opportunity to understand situations better and plan their own responses.

Donation Champion Learning Session:

Pallavi and Arati attended a Donation Champion Learning Session titled 'Supporting Families and Sharing Best Practices'. It was a day long workshop at the Lankenau Medical Center that addressed critical care staff on the following aspects:

- Role of the Donation Champion in improving organ donation outcomes
- Communicating best demonstrated practices: The optimal process
- Determination of and communication surrounding brain death
- Clinical Evaluation and Management of the potential organ donor
- Effective approach to optimizing Donation opportunities

A panel discussion on "Patient and Family Perspectives" was also a part of the workshop. The panel comprised a donor family member, a double lung transplant recipient, a potential recipient awaiting kidney transplant and an expert from Family Support Services, Gift of Life Donor Program. This gave the audience an understanding of the perspective of a donor family, the trials of awaiting a transplant and new lease of life with the help of a gifted organ

Observational Learning

Pallavi and Arati spent a day at the Transplant Information Centre (TIC) listening in to calls from hospitals regarding potential donors and counselling for tissue donation. They also observed how an In-House Coordinator manages shifting of organs from other states and does allocation as per the UNOS guidelines.

The TIC works 24X7. The TIC gets a referral within one hour of patient death or when the death certificate is completed and is provided with the basic information such as patient demographics, date and time of death, cause of death etc.

The main goal is for Gift of Life to speak with the family and offer the opportunity of tissue donation. The Gift of Life arranges for use of an OR, or transportation of the body to Gift of Life for the recovery of the donated tissue

Visit to Einstein Medical Center:

A visit to Einstein Medical Center was organized during the fellowship.

This gave them the opportunity to interact with the liver and kidney coordinators and to understand the pre-transplant counselling and post-transplant follow-up with kidney and liver recipients. They also had the opportunity to observe the multi-disciplinary team meeting on listing patients on the liver waitlist registry.

During the visit to the hospital, they were able to spend time at the HLA lab as well.

Visit to Musculoskeletal Transplant Foundation:

The fellowship offered them the unique opportunity of visiting the Musculoskeletal Transplant Foundation (MTF) located in Jessup, Pennsylvania. Mr. Barry Demanski, Associate Director- Operations took them on a tour of the entire facility. There was so much knowledge to be gained and it was fascinating to learn about the exacting standards set to ensure the quality of tissue graft.

Pallavi and Arati also had the opportunity to interact with Mr Domenick Buonocore (Vice President, Processing), Angela McCord (Manager, Donor Scheduling) and Laura Maconeghy (Manager Distribution/Inventory Control)

Life and Legacy – Honoring Organ and Tissue Donors and Their Families

Pallavi and Arati also had an opportunity to attend "Life and Legacy" - an event held to honor Organ, Tissue and Cornea Donors and their families for their generous gifts. The event was held at Blackwood, New Jersey on October 21, 2018.

During the ceremony, the families were presented with a 'Gift of Life Donor Medal' (a medal which was established to honor the gift that their loved ones' had given) and 'Wrapped in Hugs' wrap (to make the donor families feel wrapped in gratitude and love for their generous gifts). Following that there was a photo tribute during which a photo collage of the organ and tissue donors was shown. During the photo tribute, heart-warming and soothing music was played by harpist Laura Enuco.

In addition, there was also a 'Quilt Pinning' section. The donor families were encouraged to bring a quilt square in memory of their loved and those quilt squares were pinned on the 'Threads of Love' Memorial Quilt by the donor families.

There was a heart-warming sharing by a tissue recipient, a cornea recipient and a liver recipient as to how the gift of a tissue or an organ had transformed their life. A donor family member also shared his experience of gifting his daughter's tissues and organs and what the act meant to their family.



Mr. Howard M. Nathan, CEO and President, Gift of Life Donor Program presenting the mini fellowship completion certificate to Ms. Arati Gokhale

Visit to Gift of Life Family House

Pallavi and Arati visited the Gift of Life Family House, a unique initiative of Gift of Life Donor Program. The family house serves as a "home away from home" for transplant patients and their families by providing lodging and other support services at an affordable price. "Home Cook Heroes Program" was a distinct approach of Family House to engage volunteers. With a true sense of generosity, these volunteers come and prepare meals for transplant patients and families at the Family House every day.

Mr Howard M. Nathan, President and CEO, Gift of Life Donor Program, Ms. Theresa Daly, Director, Gift of Life Institute, the faculty and staff made the Mini Fellowship a warm and enriching experience.

Ms. Pallavi Kumar
Executive Director
MOHAN Foundation, Delhi - NCR

MOHAN Foundation's project "Gift Hope, Gift Life", supported by SBI Foundation wins Gold at the SKOCH CSR Awards



On 19th September 2018, MOHAN Foundation's project 'Gift Hope, Gift Life – Augmenting deceased organ donation program in India', supported by SBI Foundation, was conferred the SKOCH CSR GOLD award 2018 (Top Category), at Delhi. The CSR support lent by SBI Foundation and the commitment shown by its top management were highly appreciated. The highlights of the project were the lives that were saved through the Organ Donation Toll Free Helpline, through training of transplant coordinators, doctors, nurses and surgeons.

The 'Life Before Ashes' Campaign wins top accolades at leading advertising awards in India this year



Abby's Awards 2018

Big Bang Awards 2018

Earlier in 2018, MOHAN Foundation launched the 'Life Before Ashes' campaign, aimed at spreading a poignant yet hard hitting message – 'What has now become ashes, could have been another person's heart or kidney, if only the organs were donated'. The Foundation created a set of art installations of human organs to highlight this urgency and set the public thinking about organ donation. The human organ installations, in the shape of a heart, kidney, liver and eyes were made from a mix of real human ashes and mud from the graves and have been on display at malls and hospitals all across India.

At the Big Bang Awards 2018, organized by the Advertising Club Bangalore on 28th September 2018 at the Ritz Carlton, Bengaluru, the campaign was recognized as the 'Creative Campaign of the Year', while also winning 3 Gold, 3 Silver and 2 Bronze metals in various other categories.

At the Abby's 2018 organized by the Advertising Club Mumbai during 5-7th April 2018 at Grand Hyatt, Goa, it won 2 Gold metals along with 7 Silvers, featuring across a large number of categories including Print, Print Craft, Out of Home, Ambient, PR, Branded Content as well as Integrated. It also won 2 Golds at the Outdoor Advertising Convention Awards 2018 at Renaissance, Mumbai on 28th July 2018.

IPS Officer dedicates his marathon record to MOHAN Foundation in presence of the Tamil Nadu Governor



Dr K. Jayanth Murali, IPS completing the half marathon with 'Duct Taped Mouth'

During the Dream Runners Marathon in Chennai on July 22, 2018, Dr. K. Jayanth Murali IPS, Director Vigilance and Anti-corruption, Tamil Nadu, who has been supporting MOHAN Foundation came forward to run the half marathon to create awareness about organ donation through a special gesture. He decided to run the entire length of the half marathon by duct taping his mouth. When the mouth is taped the only option to breathe in, is through the nose and this makes running especially long distances extremely difficult. He covered the distance of 21 km in this way in 2 hours and succeeded in creating a new India Book of Records. Dr. Jayanth dedicated the achieved record (medal and certificate) to MOHAN Foundation in the presence of Honourable Governor of Tamil Nadu, Shri. Banwarilal Purohit on 30th October 2018 at Raj Bhavan, Chennai.



Honourable Governor of Tamil Nadu Shri. Banwarilal Purohit presenting Dr.K. Jayanth Murali's India Book of Records Award to the MOHAN Foundation

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Panel discussion on Ethics in Organ Donation and Transplantation moderated by Dr. Sumana Navin (left) Course Director, MOHAN Foundation

Present at the Valedictory function were Dr. Vasanthi Ramesh, Director, NOTTO and Dr. R. Kanthimathy, Member Secretary, TRANSTAN and Dr. Sumana Navin, Course Director, MOHAN Foundation. Dr. Vasanthi Ramesh wished the participants well and asked them to work with passion and to bring India on the world organ donation map. The message from Dr. R. Kanthimathy was that the transplant coordinators should adhere to guidelines and protocols to ensure smooth functioning of the organ donation and transplantation programme. The participants were awarded completion certificates.



(L to R) Dr. R. Kanthimathy, Member Secretary, TRANSTAN, Dr. Vasanthi Ramesh, Director, NOTTO and Dr. Sumana Navin, Course Director, MOHAN Foundation handing over the completion certificate to Mrs. Bharti Tamaskar from Central Railway Hospital, Nagpur



Faculty and participants at the training programme

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Mrs. Lalitha Raghuram (third from right) with participants of a group activity at the Transplant Coordination workshop

The main plenary sessions included sessions on ABO Incompatible kidney transplants, swap transplants, prevention and management of infections in solid organ transplantation, and rejection. There were also sessions on donation after brain death and circulatory death, and changes in the law in Bangladesh governing organ transplantation. Bangladesh passed the Transplantation of Human Organ act in 1999, which was amended in 2018. Some of the salient points are –

1. Definition of 'close relative' expanded to include grandparents, grandchildren and first cousins as potential living donors.
2. Allows transplant of other organs besides kidneys such as heart, lungs, intestines, liver, pancreas, and tissues.
3. Declaration of brain death - Committee of at least three specialist professors or associate professors of medicine or critical care medicine, neurology, and anaesthesiology.
4. No organ other than eyes and bone marrow can be taken from any brain-dead person if they are aged below 2 years or above 65 years.
5. Punishment (fines) enhanced up to Bangladeshi Taka one million.

A workshop – 'Update on Transplant coordination' was held at Kidney Foundation. There were 68 participants for this – ICU doctors and nurses, staff from nephrology & dialysis units.

Online Course for Transplant Coordinators

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

Highlights:

- Online course - First of its kind in South Asia
- One year (E-learning with one-week contact session)
- Ideal for working health care professionals

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