

# INDIAN TRANSPLANT NEWSLETTER

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MULTI ORGAN HARVESTING AID NETWORK

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**Editorial Desk****Organ Donation and Transplantation in South Asia**

South Asia is a densely populated region which comprises the sub-Himalayan countries and includes Afghanistan, Bangladesh, Bhutan, Maldives, Nepal, India, Pakistan, and Sri Lanka. The South Asian Association for Regional Cooperation (SAARC) is an economic cooperation organisation which was established in 1985 and includes all eight nations from South Asia. South Asia covers an area of about 5.2 million km<sup>2</sup>, which makes up 3.5% of the world's land surface area. The region is densely populated with about 1.749 billion people and this accounts for about one fourth of the world's population. Tamil Nadu has maintained its lead position in terms of the number of deceased donor transplants in India since 1995 when the transplant law was first passed in the state and it accepted brain stem death for organ donation. In the last three years it has officially received awards for the best state in deceased donation from NOTTO (National Organ and Tissue Transplant Organization) during the annual celebration of organ donation day at Delhi as it has had the highest number of deceased organ donors as shown in the table. The increasing number of deceased donors has meant a rise in the number of patients benefitting from such transplants. Hospitals that do not generate their own deceased donors too have benefitted from the 'common pool' waiting list for kidneys.

The region is also home to about 171 million diabetics (2010) and this is expected to exceed 262 million by 2030. The high incidence of diabetes and hypertension is a major cause of organ failure, especially kidney failure and the estimated incidence of end-stage renal disease is 225-275 per million population in the region.

Due to poverty, lack of universal health insurance and high cost of treatment in the private sector, the majority of the patients who suffer from end-stage organ failure in this region do not have affordable access to treatment. For example, the estimated number of new patients who develop end-stage kidney failure every year in India is about 200,000, but only a quarter are able to sustain some form of treatment whereas others withdraw and are condemned to death. Many are young, in the prime of their lives - family breadwinners or homemakers and their loss is a loss not only to the family, but also to society. Hence although the projected demand for organs is very high, when it comes to actual demand in terms of financial affordability for treatment, the numbers are much lower. It is estimated that about 50 to 60,000 new patients are having dialysis and against this only 10,000 live and about 2,200 deceased donor transplants are undertaken annually.

The current status of organ transplants in the region\* is as follows:

Country	Estimated Kidney Transplants/year	Estimated demand/year
Pakistan	625	25,000
Bangladesh	100	5,000
Sri Lanka	250	2,000
Nepal	200	3,000
India	12,400	60,000

\* Data are approximate figures and may not be accurate

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## Organ Donation Helpline Poster by MOHAN Foundation gets the Best Poster Prize at the 15th Congress of the Asian Society of Transplantation

The 15<sup>th</sup> Congress of the Asian Society of Transplantation (CAST) was held from 27-30 November 2017 in Cebu, Philippines. Over 900 delegates attended the congress. Dr Sunil Shroff, Managing Trustee, MOHAN Foundation attended the Congress as a faculty member.

The four-day conference had interesting plenary talks, insightful symposia and clinical discussions. The first day there were workshops including one on brain death. There was a wide variety of paper presentations from ethics, trainings, master classes, paediatric transplants to improved outcomes in liver, heart and renal transplant.

MOHAN Foundation presented two papers, the podium presentation was on Police Training and the poster was on Organ Donation Helpline. The presentation was highly appreciated. India seems to be the only country to conduct Police Training and have legal issues with cases that go for organ donation. The poster '**Organ Donation Helpline as a space to promote organ donation - experiences and challenges**' was adjudged the Best Poster Award at the Congress.

The abstract of the poster is given below:

### Introduction

Helplines offer professional and impartial support to callers. They are a safe trusted space for vulnerable callers. MOHAN Foundation a Non-Government Organisation in India set a free to caller organ donation helpline in August 2012 to promote organ donation.

### Methods

Calls are taken by trained counselors and transplant coordinators. A database has been developed to support the counselors. The helpline number has been promoted in websites, print and TV campaigns on Organ donation. Checks on quality of interactions are done regularly. Regular debriefing and training keeps the staff motivated.

### Results

More than 30% of callers are those who wish to register as donors. 30% of callers are patients or their family members with queries on organ procurement. Around 10% of calls are about trade in organs and organ donation after suicide. 10% of calls are about real time cases of tissue and organ donation. Internet and our website is the primary source for the number (95%). National campaign on organ donation in print and television media has resulted in a spike in calls.

### Discussion

As a NGO there is a considerable challenge for resources in today's environment of outcomes-based funding. Another challenge is to provide the service in all languages in a multilingual country. To increase the reach of the helpline MOHAN Foundation has the number on Organ Sharing websites of 2 states and as a referral on the state medical helpline of 3 states.

### Conclusion

The helpline has provided a safe space for callers to get correct information on organ donation and transplantation.

## MOHAN Foundation invited to Deceased Donor Organ Transplantation Workshop in Sri Lanka

A Deceased Donor Organ Transplantation Workshop was organised on 11<sup>th</sup> February 2018 by the Organ Transplant Unit at Sri Jayewardenepura General Hospital, Sri Lanka. Dr. Niroshan Seneviratne, Consultant Urologist & Transplant Surgeon on behalf of the Steering Committee invited the MOHAN Foundation team to be resource persons along with Dr. Arun Kumar, Professor & Head, Department of Critical Care Medicine, Saveetha Medical College & Hospital, Chennai.



**Panelists answering queries at the workshop - (from left to right) Dr. Sunil Shroff, Dr. Arun Kumar, Dr. Chinthana Galahitiyawa, and Dr. Niroshan Seneviratne**

The workshop began with an 'Overview of organ transplantation in Sri Lanka' by Dr. Lakshmi C. Somatunga, Deputy Director General of Health Services, Ministry of Health, Nutrition and Indigenous Medicine, Sri Lanka. She elaborated on the national transplant programme. It was aimed at streamlining deceased donor organ transplantation through clarifying the legal process, appointing and training donor coordinators, and developing infrastructure. There was a plan to divide the country into four zones (Northern, Central, Western, Southern) for the purpose of organ allocation. She said that the way forward was to have an allocation protocol and central allocation system in place as well as a regional ethics committee. It was important to do transplants within a legal framework keeping ethical norms, and social and cultural acceptance in mind.

Dr. Sunil Shroff, Managing Trustee, MOHAN Foundation participated in a parallel discussion with senior medical professionals and law makers from Sri Lanka regarding what was required to give an impetus to the deceased organ donation programme in the country.

## Qutab Minar Turns Green for Organ Donation



On February 17, 2018, the iconic Qutab Minar was bathed in green to highlight the cause of organ donation during the annual event by MOHAN Foundation titled 'Samarthan 2018,' held at the terrace of Qla at Mehrauli, New Delhi. Qla is part of the Kila complex, an old Musafirkhana which has been painstakingly restored. The Qutab Minar provided a magical backdrop to the venue.

The Qutab Minar was lit in green because the green ribbon symbolises hope for those who are waiting for a second chance at life through transplantation. It reminds us of the men, women and children who have died waiting for a life-saving transplant. Most importantly, it conveys our gratitude to Organ Donors and their families for giving the greatest gift of all, the gift of life.

## Organ Donation Appeal made Compelling by use of Human Ashes

'Life before Ashes' is a poignant, yet hard-hitting, message by MOHAN Foundation to spread a very simple message - 'What has now become ashes, could have been another person's heart or kidney, if only the organs were donated.' The Foundation has created a set of art installations of human organs to highlight this urgency and make the public think about organ donation.



The human organ installations are made from a mix of real human ashes and mud from graves. This idea stems from the insight that people are ready to allow their organs to be burnt and wasted, but they aren't willing to let their organs give a new life to someone. The installations are meant to make people think about the need of organ donation while also urging them to sign up and become organ donors. The art collection featuring human heart, liver, kidney and eyeball went on display at various places in Mumbai and Delhi.

## Jaipur's Kanwar Nagar Road named after Organ Donor Dikshant Thadani



*Dikshant's Mother (Left) with Mrs. Bhavna Jagwani, Convenor, MFJCF (centre) beside the road sign named after Organ Donor Mr. Dikshant Thadani*

Dikshant Thadani, 21 years old, was a resident of Jaipur's Kanwar Nagar. He saved four lives by becoming an organ donor. He met with an accident on 21<sup>st</sup> August 2017, sustained severe head injury, was certified brain dead and his family agreed for donation of his organs (liver, kidneys and heart). The counselling for donation was done by members of MOHAN Foundation Jaipur Citizen Forum- Navjeevan. Mr. Jai Kumar Thadani (Father), Mrs. Varsha Thadani (Mother) of Dikshant Thadani agreed to donate his organs.

In honour of Dikshant Thadani and his family members, Kanwar Nagar Panchayat Samiti organised a programme to name a road in Kanwar Nagar after Dikshant Thadani. On 15<sup>th</sup> February 2018, Mr. Rajiv Arora, Mrs. Bhavna Jagwani, Mr. Govind Gurbani, Mr. Sadhurrām Totlani and Mr. D. D. Ladhani unveiled the road sign with Dikshant's name on it. It was a one-of-a-kind initiative where a road was named after an organ donor.

## International Workshop on Futuristic Healthcare Technology: Telemedicine and Medical Drone held in Chennai



*Dignitaries at the inauguration of the Futuristic Healthcare Technology Workshop - (left to right) Dr. K. Ramachandra, Prof. Thais Russomano, Dr. Prathap C. Reddy and Dr. K. Ganapathy*

A two-day international workshop on Futuristic Healthcare Technology: Telemedicine and Medical Drones was held on 16<sup>th</sup> and 17<sup>th</sup> December 2017 at Apollo Children's Hospital, Chennai. It was organised by National Design Research Forum (NDRF), Bengaluru and the Institution of Engineers (India) in association with Apollo Tele Health Services (ATHS) and National Institute of Advanced Studies. The workshop was well attended with engineers, scientists, technologists, transplant surgeons, doctors, and tele health specialists participating.

The aim of the workshop was to look at how healthcare delivery could be augmented by leveraging advances in interdisciplinary engineering practice to develop affordable and innovative medical and healthcare devices. Access to better and appropriate technologies to match the health needs of the population (especially in rural and inaccessible areas) would enable disease prevention, early diagnostics, and effective treatment.

Prof. K. Ganapathy, President, Apollo Telemedicine Networking Foundation & Director, ATHS spoke on the future of telemedicine. He emphasised that technology could be effectively used in wellness, prevention, diagnosis and treatment, and that digital health programmes were the future. There was a full session dedicated to the use of drones in emergency medical care including organ transport. Dr. Kota Harinarayana, Chairman, General Aeronautics Pvt. Ltd., spoke about the challenges of medical drone operations in a civilian environment in India. He said that the flying height of drones in USA was 400 feet, in Europe it was 700 feet, while in India the Directorate General of Civil Aviation (DGCA) was looking at 200 feet in its draft guidelines. One of the other challenges he mentioned was non-availability of test facilities for drones. Dr. K. Ramachandra, Director, NDRF, elaborated on drones for organ transport. At present drones can carry a payload of up to 4 kg and cover a distance of 5 km. For organ transport, the payload would be around 25 – 40 kg, range 150 – 300 km and an endurance of 3 – 4 hours. He said it would be essential to set up virtual "air" corridors with the help of digital/aerial mapping. He felt a national programme was needed for drone operations. Prof. B. Gurumoorthy, Indian Institute of Science shared details of an active heart perfusion container called 'LifeBox.'

This has been designed by students using dry ice-based cooling for transport by drones. Dr. Sunil Shroff, Managing Trustee, MOHAN Foundation is on the National Advisory Committee for these workshops and moderated the panel discussion on 'Challenges in deploying drones in healthcare.' Dr. Shroff and the panel members discussed and debated on all the relevant aspects – regulatory & licensing, safety/reliability, operations, and practical issues related to medical drones. Some of the takeaways from the discussion were that intra-city delivery of organs could be explored first, clearances from the Indian Council for Medical Research (ICMR) and clear guidelines from the DGCA needed to be pursued. Lt. Gen. Dr. V. J. Sundaram, PVSM, AVSM, VSM (Retd.), Advisor (Micro-Nano-Bio Systems), NDRF who heads the National Advisory Committee in his summing up said that with a medical drone safety and security were of utmost importance, especially in organ transport since organs were an invaluable resource. He reiterated that certification of drones and an Air Traffic Control system for drones needed to be looked at. Following the panel discussion and interaction with the delegates, it was decided to form a Special Interest Group (SIG) to start working on the possibility of making medical drones available to facilitate healthcare in remote areas as well as for organ transport.

## 2nd Collaborative Conclave for Organ Donation held in New Delhi



**Dr. Anil Kumar, Dr. Suresh Badhan, Ms. Anika Parashar, Dr. Vimal Bhandari and Ms. Kirti Parashar during a session**

The Collaborative Conclave for Organ Donation is a common platform for all the NGOs working on organ donation in India. ORGAN (Organ Receiving & Giving Awareness Network) India, an initiative of the NGOs Parashar Foundation & the Vijaya Gujral Foundation, in association with NOTTO, (National Organ & Tissue Transplant Organization) held the Second Collaborative Conclave for Organ Donation with all the NGOs in the field of organ donation in New Delhi on November 28, 2017. It was conceived in 2016 with the vision of strategising the efforts of the Government and the NGOs to work jointly to promote the cause of organ donation, identify the loopholes and challenges faced by all stakeholders, and find solutions for the same.

More than 20 NGOs across the country were invited and 16 attended the Conclave held at the NOTTO office in Safdarjung Hospital, New Delhi. NGOs from Odisha, Tamil Nadu, Maharashtra, Rajasthan, Gujarat, Assam,

Delhi and Madhya Pradesh were present. Representatives from Karnataka and Kolkata could not make it to the Conclave but sent in their presentations, points and queries. NGOs who participated were ORGAN India, Donate Life, MOHAN Foundation, Shine India Foundation, Muskaan Group, A Million Pledges, Dadhichi Deh Daan Samiti, Zuble Foundation, Kidney Federation of India, Apex Kidney Foundation, MOTHER, Shatayu, Gift Your Organ, Light A Life, amongst others. Ms. Anika Parashar (Co-Founder, ORGAN India and Trustee, Parashar Foundation) made introductions and thanked everyone for attending the Conclave. She also moderated the Conclave, Dr. Vimal Bhandari (Director, NOTTO), Dr. Anil Kumar (Additional Deputy Director General, DGHS, MoHFW), Dr. Megha Pravin Khobragade (Joint Director, NOTTO), Dr. Suresh K Badhan (Consultant Coordination, NOTTO), Ms. Sunayana Singh (Co-Founder & CEO, ORGAN India) were all present at the Conclave along with representatives of all the NGOs.

Some of the issues that were discussed were notification of November 27 as organ donation day by the Government, one common design for donor cards issued by all agencies, including a chapter on organ donation in the MBBS curriculum, audit of outcomes in transplant patients, building awareness in school children, writing to the Film Chamber of Commerce to issue a Directive to show a short clip on organ donation before every movie.

## An interview with Dr. V. Ramadevi, Head of the Department (HOD) & Professor of Plastic Surgery, Government Stanley Medical College and Hospital, Chennai



**LET'S GIVE THEM A BIG HAND!**



*Mr. R. Narayanaswamy before the hand transplant*



*Stop press- Mr. R. Narayanaswamy two months after the hand transplant*

On 7<sup>th</sup> February 2018, history was created in the Government Stanley Medical College and Hospital, Chennai where the first double hand transplant in the state of Tamil Nadu was performed by The Institute for Research and Rehabilitation of Hand & Department of Plastic Surgery. Talking about the experience, Dr. V. Ramadevi, Head of the Department (HOD) & Professor of Plastic Surgery said that the department had always played a pioneering role, starting with Prof. R. Venkataswami (HOD from 1971 to 1991) and the successes in reconstructive surgery. Initiating a hand transplant programme was the vision of Prof. R. Krishnamoorthy (HOD from 2009 to 2011) and when she took over as HOD in 2015 she was determined to make it come to fruition. The first step was to renew the hand transplant license which was given in 2010. In addition, all the department positions were filled so that a complete team was in place. The team was enthusiastic, energetic and raring to go.

Dr. Ramadevi said that, in fact, an opportunity first arose in December 2017 with a potential unilateral hand donation. But it did not materialise due to various issues with the waitlisted recipients. While the team felt frustrated at the time, it actually turned out to be a blessing in disguise as it was a mock drill for the actual hand transplant two months later. All the flaws were ironed out, a checklist made and roles allocated. In the meantime, a number of awareness programmes were also held in the hospital and potential recipients were educated and counselled.

And then on 6<sup>th</sup> February 2018 that all important call came to the team. As luck would have it they had all just returned from the Tamil Nadu and Pondicherry Association of Plastic Surgeons' meeting in Ooty. The time had come for the team to make history. The recipient was Mr. R. Narayanaswamy, 29 years, a mason from Dindigul, Tamil Nadu who had lost both his hands in an electrocution accident. The surgery was a marathon effort that lasted 13 hours involving 35 doctors and 40 paramedical personnel. There were four teams involved – two on the donor side and two on the recipient side. Dr. Ramadevi said that the grief counsellors, Mr. S. Senthil Kumar and Mr. G. Santhosh played a key role in counselling the family of the deceased donor. The grief counsellors shared that they had six intensive sessions with the family. The uncle of the brain-dead patient was instrumental in helping the family make the decision to donate the hands, in addition to the kidneys, liver and corneas of their loved one. To the family's obvious question of disfigurement once the hands were retrieved, the grief counsellors laid their fears to rest by explaining that a prosthesis would be fixed to maintain the integrity of the body. These prostheses were fashioned in-house in the Splint section of the department.

Dr. Ramadevi said that there were some tense moments both during and post transplant, but it was tided over with the unwavering support of the anaesthetists, the nephrologist (handling immunosuppression), her own team, and the Dean Dr. Ponnambalam Namasivayam. The recipient was doing well and was undergoing hand rehabilitation.

A Hand Clinic has now been established in the department where prospective recipients are evaluated and counselled along with their families regarding the benefits and risks of hand transplant. It was inaugurated by Dr. C. Vijaya Baskar, Minister for Health & Family Welfare, Government of Tamil Nadu. At present there are 158 patients listed with about 20 for double hand transplants. The Chief Minister of Tamil Nadu, Mr. Edappadi K. Palaniswami also expressed his appreciation to the team of doctors. Many new facilities in the department have been provided through the government with the help of Dr. J. Radhakrishnan, IAS, Principal Secretary, Health & Family Welfare Department.

Dr. Ramadevi's interest is in the field of academia where she is focusing on training young plastic surgeons in techniques that will allow them to scale new frontiers in the field of plastic and reconstructive surgery. And give them the opportunity to make history once again.

Editor's note: The first hand transplant in India was performed at the Amrita Institute of Medical Sciences (AIMS), Kochi by Dr. Subramania Iyer in January 2015. Since then four more hand transplants have been performed – three in AIMS, Kochi and one in JIPMER, Puducherry.

- Dr. Sumana Navin

## Champions of Lung Transplantation



### **Vaidehi Kaza M.D., M.P.H**

**Associate Director, Lung Transplant Program  
Associate Professor, Division of Pulmonary  
Critical Care Medicine.  
University Texas Southwestern Medical Center  
Dallas, Texas**

"You cannot believe in God until you believe in yourself," quoted by Swami Vivekananda was the strongest message in my mind in the morning of a beautiful day in November 2017. It was 8 AM in the morning. I was driving to work. I was hopeful to make some headway in taking care of a patient who was very sick. I just met this patient in my clinic in the past week, and now developed acute respiratory failure. As I was parking my car, my mind was filled with these questions. Can this patient live? Can this patient get out alive from this horrific respiratory failure? Can we find a suitable pair of lungs before it's too late? My beeper, which kept ringing, interrupted my thoughts. It read, " Dr. Kaza, please call. We are primary on an offer for one of our patients. We have 30 minutes to respond." I rushed to the nearest computer. I logged into our United Nations Organ Sharing Network (UNOS). Every 10 minutes, a patient is listed for transplantation in UNOS.

The Division of Transplantation is under Office of Special programs, which is categorized under Health Resources and Services Administration (HRSA). The HRSA is governed by the Department of Health and Human Services in the United States of America. The Division of Transplantation has two service lines, Organ Procurement and Transplantation Network (OPTN), and the United States Scientific Registry of Organ Transplant Recipients (SRTR). The United Network for Organ Sharing website (UNOS) is where all patients awaiting organ transplantation are listed. The urgency for transplantation for lung transplantation is based on "Lung Allocation Score" or LAS score. The LAS score is based on wait list urgency, i.e. risk of death in the first year awaiting lung transplantation and post transplant survival, i.e. chances of survival in the first year with lung transplantation. So, sicker the patient, higher the LAS score. The first step, in organ allocation, is elimination. All the transplant candidates on the wait list, who are not suitable due to blood type, height, weight, and other medical factors, are automatically screened. Then, a secure computer application process will determine the order in which candidates will receive offers. There are 58 local donor service areas and 11 regions that are used for organ allocation. However, since heart and lungs have less time to be transplanted, radius from donor hospital is used instead of regions for organ allocation.

In the United States of America, the 58 local donor service areas are managed by Organ Procurement Organizations (OPO). The OPOs are structured to provide services such as donor family support, management of organ donors and professional education. There is an onsite OPO coordinator who takes the responsibility to take donor history, especially, social history, family history and other relevant medical history. This information along with basic labs, such as complete blood count, basic metabolic panel, liver function tests, arterial blood gas, report of chest x-ray or any other radiological imaging is uploaded into UNOS donor net website. Each of us physicians involved in organ transplantation, have secure log in identification and password. The OPO coordinator works with the donor hospital to offer option of organ donation, informed consent, coordinate organ recovery and provide follow-up information to donor family and involved hospital staff. Determination of death is by circulatory, respiratory criteria or neurological criteria as per standard guidelines. Authorizations for organ donation are usually higher when personnel with experience and expertise approach donor families. During such challenging situations, it is imperative for transplant coordinators from OPO (not from donor or recipient hospital) to be able to manage conflict between family, treating physician and hospital. The OPO coordinator is the central point in managing the donor while receiving recommendations about donor management from recipient teams.

There are multiple studies that demonstrate, improved donor lung utilization when donor management protocols are used with intensive care teams in donor hospitals. The important aspects of donor management that are included in standardized protocols are discussed below.

Brain death and prior insults disrupt the neuro-hormonal balance. The initial sympathetic surge leads to hypertension followed by neurogenic hypotension. The resulting pro-inflammatory cytokines can cause acute lung injury or capillary leak. Thus, additional volume will cause flooding and damage the lungs further. There are three major aspects of donor management for lung retrieval.

1. Volume Therapy and hemodynamics
2. Ventilator management
3. Screening for infection

1. Volume Therapy and Hemodynamics: Managing volume status is always challenging with lung recruitment. The other abdominal organs, kidney teams have liberal management strategy.



Initial assessment of volume status is done with monitoring tools such as central venous catheter, arterial line and other non-invasive measures; initial goals are central venous pressure, less than 10, mean arterial pressure 60-70 mmHg, urine output, 1-3 ml/kg/hr, left ventricular ejection fraction 45% or higher. There is no clear data for preferred resuscitation fluid; hypovolemic shock is corrected with replacement fluid available. 5% albumin as colloid is also considered in this setting.

Normal saline is not advised in hyperchloremic metabolic acidosis, ringer's lactate is not advised in hyposmolar state. Hydroxyethylstarch is contraindicated since it can cause acute kidney injury, coagulopathy, acute hypervolemia and right ventricular compromise. Once hypovolemia is corrected, management of hemodynamics is the next crucial step. Vasopressin is first line agent recommended in refractory shock. Norepinephrine or phenylephrine are used as second line for vasodilatory shock. Dopamine, dobutamine, epinephrine are used for primary cardiac pump failure. Monitoring is essential while using vasoactive drugs, with lactate, arterial blood gas, or echocardiogram, mixed venous oxygen saturation. Excessive vasopressor use can cause airway injury and lead to bronchial stenosis after lung transplantation.

2. Ventilator Management: Lung protective ventilation at 6ml/kg is a reasonable strategy. Recruitment with higher positive end expiratory pressure (PEEP) of 8-10 cm H<sub>2</sub>O, gentle diuresis with lasix is indicated. In some centers, pressure controlled ventilation directed at higher mean airway pressure to improve oxygenation is targeted. Several OPO coordinators have recruitment strategies, some of which include, increasing PEEP for a short duration of less than a minute. In addition, closed circuit tracheal suction, higher PEEP at 8-10cm H<sub>2</sub>O, decrease in fractional inspired oxygen to 50% or lower are now standard guidelines for donor management.

3. Screening for Infection: It is absolutely necessary to evaluate for donor-derived infections. Apart from routine screening serologies that are sent, evaluating for hepatitis, HIV, syphilis, additional recommendations include blood cultures, urine culture and bronchial washing for surveillance. It is important to know if donor had infection at presentation or was it hospital acquired. It is imperative to treat donor infection prior to organ retrieval. The recipient should be treated with antibiotics related to specific pathogen at least for 7-14 days after organ implantation. Bronchoscopy is standard procedure and the findings are reported in UNOS website. Airway surveillance to evaluate and suction mucus plugs, blood or aspirated material significantly improves oxygenation.

Additional therapeutic strategies include managing polyuria, electrolyte imbalance, and steroid and thyroid supplementation prior to organ retrieval. Coming back to my situation, I had several challenges in managing the potential donor. Once decision about organ donation is made, the process had to be completed within 6 hours.

The onsite OPO coordinator was the key personnel involved in keeping lines of communication open. Later, diabetes insipidus, significant polyuria leading to hypernatremia, hypotension, and liberal fluids, worsening oxygenation complicated the situation.

Following the standard donor management protocol, with minimizing fluid, use of vasopressin, bronchoscopy for airway clearance further improved oxygenation; ventilator strategies described above, gentle diuresis also improved oxygenation. General criteria for acceptance of donor lungs are PaO<sub>2</sub> on arterial blood gas of 300 or higher on 100% oxygen on the ventilator with normal PCO<sub>2</sub> and pH. Ultimately, with the tremendous coordinated effort and systems in place, lung transplantation became a reality and provided hope to person who was walking a fine line between life and death.

In summary, organ donation is the key aspect of providing hope in a recipient's life. Coordination of the process is a very important aspect and coordinators are the lifelines for these complicated, challenging, exhaustive processes. As exemplified in another one of my favorite quotes from Swami Vivekananda "Arise! Awake! And stop not until the goal is reached," opportunities are few, need is large, so let us work together to achieve our common goal of being a part of saving lives.

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## ...Editorial continued

Shortage of organs has resulted in exploitation of the poor and marginalized of the society, thus making the region prone to illegal organ trafficking. The growth of the deceased donation programme has been slow and only two (India and Sri Lanka) of the eight countries in the region have been able to take up the deceased donations programmes. Sri Lanka has recently invited MOHAN Foundation to conduct a workshop to help the deceased donation programme and improve the deceased donation rate in the country. The Buddhists in Sri Lanka have a high eye donation rate and Sri Lanka has been world famous for its successful eye donation programme and is a net exporter of corneas. If Sri Lanka can set systems in place it has generally been felt that it can improve on the deceased donation rate and help it to achieve some degree of self-sufficiency and overcome the organ shortage.





**Sujatha Suriyamoorthi**  
MIS & Programme Manager  
MOHAN Foundation

## Every accomplishment starts with the decision to try

"How am I going to restart organ donation conversation with this family" was the first thought that struck me when I saw the grief-stricken family of late Mrs. Chandra (name changed).

My journey in this programme started when I joined MOHAN Foundation in 2010 as a transplant coordinator. Myself and two of my colleagues were deputed to one of the government hospitals in Chennai as grief counsellors cum transplant coordinators. We were involved in counselling the grieving families and facilitating the donation process in the hospital. Having worked as a transplant coordinator for a few years in a government hospital, I was then promoted as Programme Manager. As Programme Manager, I only oversee these transplant coordinators placed in various government hospitals but do not really involve myself in any of the painstaking ground work.

It was a Friday afternoon and I was getting ready for an official meeting. As I was grabbing my papers, I heard the beeping sound from my phone. That was a message from my team from one of the government hospitals stating that there was a young female patient identified as brain stem dead in the hospital.

Since I knew that the 1<sup>st</sup> Apnoea test would be performed anytime and the family will be approached for organ donation, I was diligently checking my phone in between the meeting, just to be in the know of updates. At around 6.30 pm, there was a message in my inbox stating that 'Family was not willing for organ donation'. I didn't know why but I had a thought that maybe after the meeting I should visit the hospital to get the complete picture. I rang my team and informed them I will be coming to the hospital and next 30 minutes or so I was there.

I sat with my team and requested them to brief me the family conversation that has happened so far. The story unfolds as follows. Mrs. Chandra, a loving wife and a mother of two was only 27 years old. On that fateful day, the couple was returning home on their two-wheeler after visiting their relatives. Mrs. Chandra, the pillion rider fell off the bike as the two-wheeler hit the speed bump and sustained severe head injury. After two days of intensive treatment, Mrs. Chandra was declared brain stem dead.

When I further probed any particular reason why the family said no for organ donation, the team said 'No particular reason.' Then I checked about the relatives present in the hospital – it was almost everyone in the family including her husband, mother, brother and other close relatives. However, they said the husband walked out of the ICU as soon as the family was informed about the bad news. The team waited for some time for him to come back, but he didn't. Since there was not much time left, the team went ahead and approached the family for organ donation. The family members patiently listened to the entire conversation and said that they would get back after discussing with her husband, Mr. Karthikeyan (name changed). Since Mr. Karthikeyan refused to come up to the ICU, Mrs. Chandra's brother and cousins went and spoke to him about organ donation. Mr. Karthikeyan's reply was a firm 'No' and the family members conveyed the same to the grief counsellors. They also requested the counsellors not to disturb them.

This was the frame that I got from my team. I sat down for some time and recalled the conversation path that my team had so far with the family. The following were the two concerns that made me decide to go back to the family and continue the conversation.

- *The family's immediate response for organ donation was not 'No' – There may be still a chance for them to reconsider their decision, if they could persuade Mr. Karthikeyan.*
- *Is there any internal conflict that Mr. Karthikeyan is going through which is probably blocking him from taking a major decision?*

I checked with my team whether it is alright if I make another attempt with the family. With their acceptance, we went back to the family and restarted our conversation with a 'Sorry'. I expressed my genuine concern to the family and I told them that my intention to come back to them is not really about their decision; but to care for their psychological needs at that sheer grieving moment.

A lot of conversation happened not only with the family but also with the extended relatives to make sure that they understood the concept of brain stem death and organ donation. In fact they mentioned that 'donation' was not something new for them as they had donated Mrs. Chandra's father's corneas a few years back.

On further probing as to why they denied consent for organ donation, her brother said 'our life is never going to be the same or whole again; neither of us is able to think anything beyond'. With a lot of empathy, we echoed the family's statement "We understand that your life is never going to be whole again. But do you think that you can still do something to make Mrs. Chandra's life whole." We knew that this might not reduce their sorrow, yet could provoke their thoughts to find a meaningful way to say goodbye to Mrs. Chandra. After a minute-long silence, Mrs. Chandra's cousin brother stepped in and said "We will try and bring her husband here. Could you speak with him about this?"

With the promise that we would not make Mr. Karthikeyan burdened with decision making, we were waiting for him in the corridor. It was 11.30 in the night and the unit was absolutely silent. I could feel butterflies in my stomach as I was completely clueless as to what Mr. Karthikeyan was going through. Every second seemed to be an hour and every little noise sounded like footsteps that were approaching us.

...continued on page 9



## Metro Retro - A Celebration of Life



**The renowned Carnatic music vocalists Mrs. Ranjani & Mrs. Gayatri performing at the concert**

There was music in the air at Vadapalani Metro Station, Chennai on 3rd December 2017. In a first-ever musical event, a Carnatic music concert was organised at a Metro Rail Station in India. The event was organised to celebrate the Golden Jubilee of the first heart transplant in the world and to acknowledge heart transplants being done in India, more so in Tamil Nadu. The concert was organised by MOHAN Foundation in honour of its 20th anniversary, in celebration of its journey in giving the 'Gift of Life' through organ donation. Dr. J. Radhakrishnan, IAS, Principal Secretary, Health and Family Welfare, Govt. of Tamil Nadu was the Chief Guest.

*...continued from page 8*

To end our waiting Mr. Karthikeyan arrived at the ICU. After a brief introduction, the conversation was again started but this time I decided to go back to the accident history. Why because, we clarified that Mr. Karthikeyan was not only primed about his wife's poor prognosis often, but also well explained about brain stem death. Hence I believed that the issue was not anywhere around understanding her condition or not accepting her death.

Finally Mr. Karthikeyan started talking about that fateful evening. After visiting their relatives, the couple was getting ready to leave but the relatives told them to stay back as it was getting dark. Mrs. Chandra who didn't know what to do, looked at her husband. Mr. Karthikeyan was determined to leave and told to her "Let's go, Chandra." Mrs. Chandra simply listened to him and the couple left the place.

"Neither I listened to my relatives, nor I asked her what she wanted to do. If I had not decided to leave, she would not have suffered." As he was saying that, he started weeping and tears started rolling down his cheeks. He covered his face with a handkerchief and leaned on the wall.

Yes, 'guilty of decision making', was the inner conflict that Mr. Karthikeyan was struggling with. His posture was an open invite for anyone that he wanted somebody to support him. As counsellors, we were left to address many issues - his guilt, grief and facilitating the entire family to take an important decision; and that was immensely challenging.



**Dr. J. Radhakrishnan, IAS, Principal Secretary, Health and Family Welfare, Govt. of Tamil Nadu honouring a 13-year-old deceased donor, Aishwarya's mother Ms. Rama and uncle Mr. Sathyaprakash**



**Mrs. Ranjani & Mrs. Gayatri along with Dr. Sunil Shroff and Mrs. Lalitha Raghuram supporting organ donation**

A lot of positive affirmation was given to him to help him to handle his guilt feeling. He was also made aware that by not taking a decision now, he might again experience the same because the other members in the family were positive about organ donation.

He then went on to discuss with the rest of the family members about donating Mrs. Chandra's organs. After an hour's discussion within the family and clarifying their doubts with us about the procedure, the family took a uniform decision to donate Mrs. Chandra's organs as well as tissues.

There was a major delay in performing the 2nd Apnoea test due to her electrolyte imbalance. But the family was extremely supportive; in fact they told us not to worry about the delay. By reading our nervousness, one of her cousins came to us and said "We don't see this as a delay as long as a precious life could be saved through her donation."

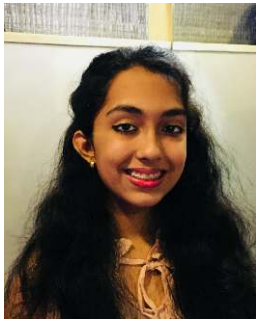
Mrs. Chandra's kidneys, liver, corneas and heart valves were donated on 18th June 2016.

Yet another remarkable family; yet another learning experience.

Acknowledgement:

- Rajiv Gandhi Government General Hospital (RGGGH), Chennai
- Team of grief counsellors cum transplant coordinators from MOHAN Foundation deputed to the RGGGH to facilitate deceased organ donation

## His Heart Will Go On...



Divya Jairam

Little Elaine tightly held her mother's petite hand out of nervousness, because of the new surroundings. 'Where are we going, Ma?' she asked, probably for the seventh time. 'Be patient, dear', her mother replied, for the seventh time. Elaine looked out of the taxi's window, while impatiently tapping her feet. She soon fell asleep. Elaine was awoken by the immediate halting of the cab, much to her happiness. She eagerly got off the cab, still holding her mother's hand firmly.

Her eyes wandered on either side of the street. The streets were surrounded by greenery as far as Elaine's tiny eyes could see. Mrs Williams guided Elaine to a huge, modern residence, which was very unfamiliar to Elaine.

As her mother rang the doorbell, Elaine waited, wondering what was the reason behind her mother's secrecy. After a moment or two, the door opened, revealing a tall and young gentleman, dressed in a rather formal attire, with a nervous smile plastered across his face. 'Mrs Williams, pleasure to meet you', he greeted. Mrs Williams shook the hand he had extended and gestured Elaine to do the same. Elaine was a pretty shy girl and not one to mingle with strangers. But she did what her mother asked her to.

'That's a very beautiful dress, Elaine', said the man.

'T-thank you', she said, nervous enough to not even make eye contact.

'Please, come inside', the man said, making way for us to enter.

They entered his house and took a seat on the modern couch, much too modern for Elaine and her mother, considering they both lived in a rather out-dated house with very obsolete gadgets. 'How are you recovering, Mr Johnson?' Mrs Williams asked the man, after he had seated himself opposite the mother and daughter.

'Were you sick, Mr Johnson?' Elaine asked, out of the blue. She hated when anyone was ill, and definitely hated hospitals. 'Because I had flu two weeks ago', she added.

Mr Johnson chuckled, and said – 'Please, call me Ed. And yes, I'm much better, thank you.'

He then looked at Elaine and replied – 'Well, I was unwell, but now with the doctor's help, I'm much better, Elaine'. Elaine nodded.

'Elaine, do you want to see the toy room we have over here?' he asked.

'There's a separate room for that?? Can I go, Ma?' Elaine asked, springing up from her seat.

'Of course, sweetie', her mother allowed.

Elaine hurriedly followed Ed into a newly furnished room, with a variety of toys that she would have never thought existed. 'Are they for me?' she asked. 'Yes, of course!' he replied. Elaine hugged the stranger immediately and he was taken aback. She ran and started playing, while the man made his way back to Mrs Williams.

Are you positive she'll take the news well?' Ed asked Mrs Williams. 'I hope, because she was very close to her dad', she replied.

He nodded and looked out of the window, into infinity. A while later, Mrs Williams called Elaine out into the living room. 'But I wanna play!' she sulked.

'There's a thing I wanna tell you, Elly', her Mother started. Elaine sat next to Ed and listened to her mother. 'So, do you know where daddy is, darling?' Mrs Williams asked, taking a deep breath after her sentence.

'Yes, you said he went to God to ask for a doll for me', she replied, innocently.

'Yes, but I want to tell you something else too. Your father, he-' Mrs Williams couldn't complete her sentence without tearing up.

'May I?' Ed asked, much to Mrs Williams' surprise. She nodded.

'You know, your daddy is a hero', he started, smiling.

'Like Superman?' Elaine asked.

'No, even better', Ed said.

'Did he save our city from evil guys?' Elaine asked.

'Not really, but he saved my life. I was sick, and he is God to me. There is no one else that I'd worship but him. My heart had stopped working, and your daddy, our superhero, gave me his own heart', Ed said, waiting for Elaine's reaction.

Elaine paused for a second, trying to digest all the information she had just received in a minute. After processing all of it, something unexpected happened.

Elaine placed her ear on Ed's chest, listening to his heart beat. Her eyes filled with tears of joy, and she knew her dad was really a superhero. Much better than superman, batman or any other. Ed embraced the little child, looking up towards heaven, as if trying to thank his heart donor. Elaine stayed there for what seemed like forever, and started talking to her "father".

'I've missed you, daddy. And I know you might not get me a doll, but you got Ed a heart, and I'm so proud of you. Thank you for everything Daddy, and Ed wants to say something, too', Elaine said, which made her mother smile.

'Yes, thanks Mr Williams. Thank you for saving my life, and when I say thanks, I mean not only me but my whole family as well. I was born with all the riches and luxuries of life, but the greatest treasure I could have gotten was the gift of rebirth, that you gave me. You're not only a superhero to your lovely daughter, but also to me and my entire family. I sincerely thank you, sir,' Ed said, joining his hands as if praying.

Elaine and Ed talked for a very long time, after which it was time to leave. While at the threshold, Elaine looked at Ed and asked him a question.

'Ed, can I call you "dad"?''

'I don't see why not, Elly', he said, hugging the innocent kid. He was a hero, not only to me, but also my family.

Ms.Divya Jairam  
9th Grade, Euro School  
Thane, Maharashtra



## MOHAN Foundation receives awards at the 8<sup>th</sup> INDIAN ORGAN DONATION DAY



On Nov 27, 2017, National Organ & Tissue Transplant Organisation (NOTTO) celebrated the 8<sup>th</sup> Indian Organ Donation Day at Constitution Club Annexe, New Delhi. Special Guests of Honour were Shri Ashwini Kumar Choubey, Hon'ble Minister of State, MoHFW and Ms. Anupriya Patel, Hon'ble Minister of State, MoHFW.

MOHAN Foundation won the award for the "Best performing NGO in India in the field of organ donation," Ms Pallavi Kumar Executive Director, MOHAN Foundation Delhi-NCR received the award. Other NGOs like ORGAN India (Delhi), Muskan (Indore) and Zublee Foundation (Assam) were also felicitated for their efforts.



Mr. P. Periyannayagam, Transplant Coordinator, MOHAN Foundation deputed in Rajiv Gandhi Government General Hospital, Chennai, Tamil Nadu was awarded second prize for his services towards the deceased organ donation program for the year 2016-2017. He received the award from Ms. Anupriya Patel, Minister of State, Union Ministry of Health and Family Welfare.

Urging all to come forward and donate their organs, Smt. Anupriya Patel said that apart from promoting organ donation, it is important to improve infrastructure and capacity of government hospitals for undertaking transplantation so that even those who cannot afford transplantation may also benefit. Smt. Anupriya Patel also administered the pledge to the participants to donate organs.

## Government of Tamil Nadu presents MOHAN Foundation with Best Performing NGO and Best Transplant Coordinator Awards

To commemorate National Organ Donation Week, Department of Health and Family Welfare, Government of Tamil Nadu organized an event at the Kalaivanar Arangam, Chennai on 24th November 2017.

Mr. Edappadi. K. Palaniswami, the Chief Minister of Tamil Nadu was the chief guest. Mr. O. Panneerselvam, Deputy Chief Minister, Dr. C. Vijaya Baskar, Minister of Health and Family Welfare, Ministers from various other Departments, Dr. Girija Vaidyanathan, IAS, Chief Secretary to the Government, Dr. Vimal Bhandari, Director, National Organ & Transplant Organization, Dr. J. Radhakrishnan, IAS, Principal Secretary, Health and Family Welfare Department and various other government officials graced the event.

MOHAN Foundation was recognised as Best Performing Non-Governmental Organisation (NGO) for promoting deceased organ donation and transplantation. Dr. Sunil Shroff, Managing Trustee, MOHAN Foundation received the award from Mr. Edappadi K. Palaniswami.



Ms. A. T. Sunitha, MOHAN Foundation who has been deputed at the Rajiv Gandhi Government General Hospital was one of the four transplant coordinators who was presented the Best Transplant Coordinator Award during the event.

## MOHAN Foundation's Transplant Coordinators in Madurai and Chennai felicitated



Mr. S. Venkatesh, Transplant Coordinator, MOHAN Foundation deputed in Government Rajaji Hospital, Madurai, Tamil Nadu was felicitated by Dr. C. Vijaya Baskar, Minister for Health and Family Welfare, Government of Tamil Nadu for his services towards the deceased organ donation programme in November 2017.

Mr. R. Ragavan, Transplant Coordinator, MOHAN Foundation deputed in Rajiv Gandhi Government General Hospital Chennai, Tamil Nadu was felicitated for his services towards the deceased organ donation programme on Republic Day 2018.

# Training Programme

MOHAN Foundation conducted one-week Transplant Coordinators' Training Programmes under the aegis of National Organ & Tissue Transplant Organisation (NOTTO), Directorate General of Health Services, Ministry of Health & Family Welfare, Govt. of India in Wardha, Maharashtra; Raipur, Chhattisgarh; and Pune, Maharashtra. This was the first time such a training programme was being held in Wardha and Raipur.

## Transplant Coordinators' Training Programme held in Wardha, Maharashtra

Under the aegis of NOTTO and Regional Organ and Tissue Transplant Organization (ROTTO) and State Organ and Tissue Transplant Organization (SOTTO) Mumbai, MOHAN Foundation in collaboration with Zonal Transplant Coordination Center (ZTCC) Nagpur, Datta Meghe Institute of Medical Sciences (DMIMS) and Acharya Vinoba Bhave Rural Hospital (AVBRH) conducted a one week Transplant Coordinators' Training Programme from 20th to 24th November 2017 at Jawaharlal Nehru Medical College (JNMC), Sawangi (Meghe), Wardha. 52 candidates were present not only from Maharashtra, but also Tamil Nadu, Assam, Haryana and Manipur. This training was supported by SBI Foundation. This was the 50<sup>th</sup> training programme conducted by MOHAN Foundation and the 16<sup>th</sup> in partnership with NOTTO.

Dr. Rajiv Borle, Hon. Vice Chancellor, DMIMS (DU), Dr. Babaji Ghewade, CMS, AVBRH, Dr. Chandrashekhar Mahakalkar, Additional Medical Superintendent (Quality), AVBRH, Dr. Vibhavari Dani, President ZTCC, Nagpur were present at the inauguration. MOHAN Foundation was represented by Mrs. Lalitha Raghuram, Country Director, Dr. Ravi Wankhede, Honorary Director, Nagpur & Secretary, ZTCC-Nagpur, Dr. Sumana Navin, Course Director and Ms. Ann Alex, Programme Associate. Present at the Valedictory function were Dr. Babaji Ghewade, CMS, AVBRH, and Dr. Chandrashekhar Mahakalkar, Additional Medical Superintendent (Quality), AVBRH who gave away the completion certificates to the participants.



(From R-L) Mrs. Lalitha Raghuram, Dr. Chandrashekhar Mahakalkar, Dr. Babaji Ghewade, Dr. Rajiv Borle, Dr. Vibhavari Dani, Dr. Ravi Wankhede, Dr. Sumana Navin and Ms. Ann Alex displaying ITN-50 at the inaugural function.



Participants displaying their poster on organ donation



Participants eager to answer questions during the Quiz



Participant receiving completion certificate at the valedictory function



Group Photo with the participants

## Transplant Coordinators' Training Programme organised in Raipur, Chhattisgarh



Dr. Punit Gupta, Nodal Officer, Chhattisgarh Human Organ Transplant Organization speaking at the inauguration of transplant coordinators' training programme

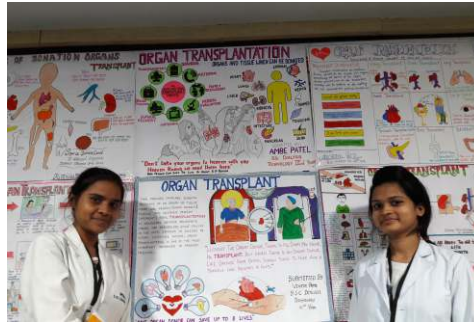


Mr. Subrat Sahoo, Principal Secretary, Health, Family Welfare and Medical Education, Govt. of Chhattisgarh speaking at the inauguration of the CME

Under the aegis of NOTTO and ROTTO Mumbai, MOHAN Foundation in collaboration with Chhattisgarh Human Organ Transplant Organization, Raipur conducted a one-week Transplant Coordinators' Training Programme from 2<sup>nd</sup> to 6<sup>th</sup> February 2018 at B. R. Ambedkar Hospital, Raipur. There were 46 participants – 35 from the government sector and 11 from the private sector. The training was supported by DKS Post Graduate Institute and Research Centre (DKSPGI) and the Tata Trusts. This was the 51<sup>st</sup> training programme conducted by MOHAN Foundation and the 17<sup>th</sup> in partnership with NOTTO.



Organ Donation Pathway activity



(left to right ) Ms. Ambe Patel and Ms. Vinita Patel in front of their posters on organ donation



Dr. Sumana Navin presenting a faculty certificate to Dr. Suresh Singh, Urologist, DKSPGI

The training was integrated with a CME on 'Intensive Care and Brain Death.' Mr. Subrat Sahoo, IAS, Principal Secretary Health, Family Welfare and Medical Education, Government of Chhattisgarh was the Chief Guest. He emphasised that an attitudinal change in all stakeholders (administrators, health care professionals and legal experts), awareness drives and fine tuning of processes were required if the organ donation and transplantation programme was to be successful in the state.

## Transplant Coordinators' Training Programme held in Pune

Under the aegis of NOTTO and ROTTO-SOTTO Mumbai, MOHAN Foundation in collaboration with Zonal Transplant Coordination Centre (ZTCC) - Pune conducted a one-week Transplant Coordinators' Training Programme from 19<sup>th</sup> to 23<sup>rd</sup> February 2018 at ISCCM Pune Office, Off Karve Road, Pune, Maharashtra. There were 51 participants not only from different places in Maharashtra, but also Tamil Nadu, Karnataka, Rajasthan, West Bengal and Delhi. This was the 52<sup>nd</sup> training programme conducted by MOHAN Foundation and the 18<sup>th</sup> in partnership with NOTTO. The training programme was supported by the Tata Trusts.

Dr. Kapil Zirpe, National President ISCCM, Dr. Subhal Dixit, Chairman, ISCCM Pune Branch, Dr. A. G. Huprikar, Secretary, ZTCC-Pune and Mrs. Arati Gokhale, Central Coordinator ZTCC-Pune were present at the inauguration. MOHAN Foundation was represented by Mrs. Lalitha Raghuram, Country Director, Dr. Sumana Navin, Course Director, Ms. Pallavi Kumar, Executive Director, Delhi-NCR, and Mr. Amit Shenoy, Project Manager – Hospital Outreach Program, Mumbai.



(L-R) Mrs. Arati Gokhale, Central Coordinator ZTCC-Pune, Dr. Subhal Dixit, Chairman, ISCCM Pune Branch, Dr. Kapil Zirpe, National President ISCCM, Mrs. Lalitha Raghuram, Country Director, MOHAN Foundation, Dr. A. G. Huprikar, Secretary, ZTCC-Pune and Dr. Sumana Navin, Course Director, MOHAN Foundation during the inaugural function



Ms. Rohini Sahasrabudhe speaking about care of recipients



Completion Certificate presentation to Dr. Sagar (l-r) Dr. Sumana Navin, Dr. Suresh Badhan, Dr. Atul Mulay and Mrs. Arati Gokhale



Ms. Pallavi Kumar (standing) moderating the role play

At the valedictory function, two of the participants, Dr. Madhavi Salunke and Dr. Sagar Bedkihal recited poems on organ donation that they had felt inspired to write. Mr. Shrikant Patwardhan, volunteer with ZTCC-Mumbai shared his thoughts on saving lives through organ donation. Dr. Atul Mulay, Committee member, ZTCC-Pune and Dr. Suresh Badhan, Consultant – Coordination, NOTTO congratulated the participants on finishing the training programme and presented the completion certificates to them.

## MOHAN Foundation participates in Mini Fellowship in Organ Donation at Gift of Life Institute, Philadelphia, USA

Dr. Sumana Navin, Course Director and Ms. Sujatha Suriyamoorthi, Manager-Information Systems & Programme Manager, MOHAN Foundation underwent Gift of Life Institute's (GOLI) Mini Fellowship in Organ Donation from 23<sup>rd</sup> October 2017 to 3<sup>rd</sup> November 2017 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 programme 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.

Gift of Life Donor Program, Philadelphia is a non-profit Organ Procurement Organization (OPO) that serves eastern Pennsylvania, southern New Jersey and Delaware. It is the largest OPO in the country and had 540 donors in 2016 that resulted in 1,412 transplants (49 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 (United Network for Organ Sharing) allocation policies. All these aspects were covered by the experts during the following didactic sessions.

- Gift of Life Donor Program - Overview
- Brain Death Pathophysiology & Neurological assessment
- Pulsatile Preservation
- Donor Management and Pharmacology
- Organ Allocation
- Role of Transplant Coordinators in Operating Room
- Family Support Services
- DCD Donation
- Serological Testing
- Donor Physical Assessment
- Professional Education - E-learning Services
- Clinical Staff development
- Hospital development
- Data Collection
- Public Education

### Observational Learning:

- Multi organ procurement process (Liver, Kidneys and Lungs) - Nazareth Hospital, Philadelphia
- Tissue retrieval process (full thickness skin, bone, tendons, fascia and ligaments) - Gift of Life Donor Program, Philadelphia

### Visit to Musculoskeletal Transplant Foundation:

The fellowship offered them the unique opportunity of visiting the Musculoskeletal Transplant Foundation (MTF) located in Jessup, Pennsylvania. MTF is a not-for-profit service organization and is the largest tissue bank in the world that is dedicated to helping people in need of tissue by providing them high quality grafts. Mr. Ted Bender, Director 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.



Dr. Nai Liang, Director, Pulsatile Preservation, Gift of Life Institute



Home Cook Heroes at the Gift of Life Family House



Ms. Lara S. Moretti, Family Support Services (L) and Mr. Rick Hasz, Clinical Services (R) from Gift of Life Donor Program at 'Life and Legacy' - A celebration to honor organ and tissue donors and their families



Mr. Howard Nathan, President and CEO, Gift of Life Donor Program, Philadelphia

### Visit to Einstein Medical Center:

The visit to Einstein Medical Center gave them the opportunity to observe the pre transplant counselling and post transplant follow-up with kidney and liver recipients. They observed the multi-disciplinary team meeting on listing patients on the waitlist registry, as well as a QAPI (Quality Assurance and Performance Improvement) meeting.



Mr. Ted Bender, Director, Musculoskeletal Transplant Foundation (MTF), Jessup, Pennsylvania

## Donation Champion Learning Session:

Dr. Sumana and Ms. Sujatha also had an opportunity to attend the 'Donation Champion Learning Session' - a day long workshop that addressed critical care staff on determination of brain death, best practices for referring the potential organ donors to OPOs, maximizing the clinical evaluation and donor management and supporting the families of potential organ donors.

A panel discussion on "Patient and Family Perspectives" was also a part of the workshop. The panel comprised a donor family member, a liver transplant recipient, a potential recipient awaiting kidney transplant and an expert from Family Support Services, Gift of Life Donor Program. While speaking, Mr. John Branton, liver transplant recipient shared that waiting for an organ was the most harrowing experience. He also added that among many other factors the 'Patient Support Group' was the one which really helped him to cope with the feeling of uncertainty and vulnerability.

Ms. Carol McCloud, a donor mother shared that donating her son's organs helped her to come out of her grief. Deciding to donate his organs, thus saving the lives of many was helping her to live her life after her son had passed away. Mr. Bill Murray, a kidney failure patient awaiting a transplant shared his experience. He said that his life was revolving only around diet, dialysis and visiting his doctor. He also added that he was waiting for that one phone call about an organ being available which might come sometime between that day and years from now, or might not come at all.

The workshop also had case study discussions on approaching donor families and donation after circulatory death.

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

Dr. Sumana and Ms. Sujatha also had an opportunity to attend "Life and Legacy" - an event held to pay tribute to organ and tissue donors and to honor their families for their generous gifts. The event was held at Bear Creek Mountain Resort and Conference Center, Macungie, Pennsylvania on 29th October 2017.



*Ms. Sujatha Suriyamoorthi and Dr. Sumana Navin receiving the mini fellowship completion certificate from Mr. Howard M. Nathan (left), CEO and President and Ms. Theresa Daly (right), Director from Gift of Life Institute*

MOHAN USA, Inc. is a 501(c) (3) registered nonprofit 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](http://www.mohanusa.org))

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, heartwarming and soothing music was played by harpist Louis Lynch.

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.

## Unique Learnings:

### Training and Education:

Gift of Life Institute focuses on providing innovative training and education to donation and transplant professionals worldwide. To help them attain proficiency in the field, it imparts action oriented comprehensive learning. Every course has a robust curriculum and consists of skill-based activities and discussions. It also offers e-learning courses to meet the global training needs.

### Family Support Services:

Family Support Services of Gift of Life Donor Program works extensively towards assisting the donor families to deal with their loss. Following are some of the services offered to the donor families

- *Speaking with Gift of Life Donor Program's counselors*
- *Pennsylvania Donor Family Grief Counseling*
- *Facilitating communication between the donor family and recipients*
- *Donor Remembrance Ceremony*

The Family Support Services sends a 'Donor Recognition Kit' immediately after donation in case the donor families prefer to keep the kit during the funeral service. The kit consists of an appreciation certificate, a medal, a pin and a wristband with a message "Be an Organ Donor".

## Gift of Life Family House

During their fellowship, they had the opportunity to stay at 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. Sujatha Suriyamoorthi

At **Novartis**, we discover and develop breakthrough medicines and find new ways to deliver them to as many patients as possible. We use science-based innovations to help patients improve their quality of life. In other words, we

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