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The Editor, ITN Desk
MOHAN FOUNDATION
Toshniwal Building, 3rd floor
267, Kilpauk Garden Road, Kilpauk
Chennai – 600 010.
Tel : 44-2644 7000
Email: info@mohanfoundation.org
Website: www.mohanfoundation.org

Editorial Desk

MOHAN Foundation signs landmark MoU with NHS Blood and Transplant, UK to increase organ donation rate in India & UK

MOHAN Foundation (MF) signed a landmark Memorandum of Understanding (MoU) with NHS Blood and Transplant (NHSBT), UK on 30th January 2015 in Chennai. The objective is to promote collaboration and knowledge sharing between the two organisations with the aim of increasing the organ donation rate in India and UK. The MoU was signed in the presence of Dr. J. Radhakrishnan, IAS, Principal Secretary, Health and Family Welfare, Government of Tamil Nadu, at the culmination of the Advanced Workshop (2nd consultative meeting) for senior transplant coordinators organised by MF.

The signatories of the MoU were Prof. James Neuberger Associate Medical Director for Organ Donation and Transplantation, NHSBT and Dr. Sunil Shroff, Managing Trustee, MF. Also present were Dr. Satya Vrat Sharma, MBE, Chair, Promoting Organ Donation (POD), UK and Chair of the MoU Steering/ Implementation Group, Dr. N. Sridhar, Former NHSBT Regional Director for Organ Donation, Midlands, UK and presently Senior ICU consultant, Intensive Care Unit, Kauvery Hospital, Chennai, Dr. Samiran Nundy, Emeritus Consultant, Gastroenterology & Liver Transplant, Sir Ganga Ram Hospital, New Delhi and Dr. Christopher Taylor Barry, Liver transplant surgeon and Founder bLifeNY, USA and Advisory Board Member, MF.

MF will work with NHSBT to help improve organ donation rates among Asian, Black and Minority Ethnic communities in the UK. These communities have a higher incidence of diabetes, heart and kidney disease that often result in organ failure and require a lifesaving transplant. There are currently 6,871 people on the transplant list, including 1071 British Asian people. The NHSBT in turn will help MOHAN Foundation with their expertise to help improve organ donation rates in India.

IN THIS ISSUE

Dr. Sunil Shroff said, "An inspiring example is the work of MOHAN Foundation's transplant coordinators based at the Rajiv Gandhi Government General Hospital, Chennai. Between February 2010 and December 2014, the families of 160 brain dead patients were counselled about organ donation and 106 families said 'yes' – making the choice to donate the organs of their loved ones to perpetuate life rather than having the organs buried or cremated. This is a 66% consent or conversion rate, which is comparable to that in the West." He added that the collaboration had come about because of the initiative shown by Dr. N. Sridhar.

The MoU was reaffirmed in the UK on the 26th of February 2015 at the House of Lords, London. The event was hosted by Baroness Finlay of Llandaff, President of the British Medical Association. The MoU was signed by Mr. Ian Trenholm, Chief Executive of NHSBT and Dr. Sunil Shroff. During the event a first-of-its-kind in the world "Organ Donor Optimisation" mobile app was launched for intensive care units. This app will help new transplant programmes in optimising potential organ donors who are brain dead and where the relatives have agreed to donate their organs. The app was developed by Dr. N. Sridhar in partnership with MOHAN Foundation and Medindia.net and is available for Android phones and Apple iPhones.

(Photo spread...on page 6 & 7)

Confucianism and Organ Donation in China

Between 6,000 and 9,000 transplants are done in China each year, a fraction of the roughly 300,000 needed, according to government data. A nationwide organ donation system was launched by China's government in February 2013, before which organs were donated through local programmes or arranged case by case. In 2014, about 1,700 people contributed organs through the new system resulting in an organ donation rate of 1.2 per million population. This has been largely through the efforts of transplant coordinators.

The job of transplant coordinators is particularly hard because many Chinese believe that an intact body is needed in the afterlife, and coordinators usually face a protracted struggle with extended families when it comes to organ donation. "The body, hair and skin are received from the parents and one dares not harm them," says one Confucian teaching. In addition, prior consent by the donor doesn't constitute legal permission in China. In practice, the system requires written consent from all living members of the immediate family, including parents, adult children and spouses, according to Gao Xinpu, deputy director of the medical affairs department at the China Organ Donation Management Center, which helps train coordinators and operates under the Red Cross Society of China. The Red Cross donation management centre has certified 547 coordinators across the country, and is training thousands more.

Successful Transplants of Hearts Donated after Circulatory Death in Australia

In a world first, surgeons at St Vincent's Hospital, Sydney, Australia successfully carried out transplants of hearts that were donated after circulatory death (DCD) in 2014. These transplants come as the result of combined research between the Victor Chang Cardiac Research Institute and St Vincent's Hospital. The two clinics created a special preservation solution which works in conjunction with a "heart in a box" machine, known as the ex vivo organ care system (OCS). The OCS allows the donor heart to be connected to a sterile circuit which restores the heart beat and keeps it warm, limiting the adverse affects associated with previous methods which saw hearts kept in an ice box.

Described as the biggest heart transplant breakthrough in a decade, the successful surgery has profound implications for reducing the shortage of donor organs, the director of St Vincent's Hospital Heart Lung Transplant Unit, Professor Peter MacDonald, said in October 2014. Previously transplant units relied solely on donor hearts from brain dead patients whose hearts were still beating.

The patient who had the transplant in October 2014 was Jan Damen, 43 and a couple of months prior to that Michelle Gribilar, 57, became the first person to have the procedure done. Ms. Gribilar was suffering from congenital heart failure. She is recovering well and said that she "feels like she is 40" since the transplant. She added that prior to the operation she had not been able to walk 100m without trouble. Now she walks 3km and climbs 100-120 stairs every day.

The second patient, Jan Damen also suffered from congenital heart failure and had surgery in October 2014. He was still recovering at the hospital at the time the news was reported. "I feel amazing," the father-of-three said, "I'm just looking forward to getting back out into the real world." The former carpenter said he often thinks about his donor. "I do think about it, because without the donor I might not be here," he said.

Cardiothoracic surgeon Associate Prof. Kumud Dhital, who performed the transplants with hearts donated after circulatory/cardiac death (DCD), said, "The incredible development of the preservation solution with this technology of being able to preserve the heart, resuscitate it and to assess the function of the heart has made this possible."

Shortage of Organs for Transplant in Canada can be overcome

The Canadian Institute for Health Information released a study which says that Canada could reduce its constant shortage of organs for transplant by harvesting more organs from older donors. For example, fewer than 10 percent of organ donors in the state of Manitoba are over the age of 60. Another way would be to allow transplants from donations after circulatory/cardiac death (DCD). On a positive note, Manitoba has the largest number of non-Caucasian population who are donors in Canada. Dr. Faisal Siddiqui, an organ donation physician with Transplant Manitoba's Gift of Life programme, says that is something to be very proud of. Another matter to be appreciated, according to him is that Manitoba has a high number of organs transplanted per donor. "We're at 4.3 organs per donor, compared to a province like Quebec at only 3.2," he says. Kathleen Morris, who is with the Canadian Institute for Health Information, says that it is very important that people sign up to be a donor and express their willingness to donate to their family. This gives the family something to go by if they're asked to make that difficult decision.

Man undergoes Five Organ Transplants at a go

Bartolomej Pesta from the Czech Republic underwent five organ transplants in a rare and pioneering lifesaving operation in December 2014. He was diagnosed with cirrhosis of the liver five years ago, and the condition caused damage to several of his organs. The 60-year-old's condition was so severe that in addition to a liver transplant he needed a new stomach, small intestine, spleen, and pancreas. Pesta waited eight weeks for the organs to become available, and underwent a 10-hour surgery at the Institute for Clinical and Experimental Medicine in Prague. He was discharged from hospital at the beginning of January 2015. Director of the transplant surgery department Jiri Fronek said, "It is great to see him doing so well." Pesta reported feeling great. "They have given me my life back," he said, "Everything is pretty much back to normal. I am on diet and have some restrictions, but I can essentially eat some normal food. Now I'm looking normal, feeling better, and I enjoy every day with my family."

FORM - IV

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I, Sunil Shroff, hereby declare that the particulars given above are true to the best of my knowledge and belief.

Sd/-
Sunil Shroff
Date: 28th February 2015 Signature of Publisher

Rajasthan on the deceased organ donation map

February 2015 saw two incredible families in Rajasthan taking the decision to donate the organs of their deceased children to help others live. The first deceased organ donor in the state was a 7-year-old boy Mohit Kumar who became brain dead following an accidental head injury. His family went on to donate his kidneys and liver on 6th February 2015. Both the kidneys were transplanted into a 50-year-old man at Mahatma Gandhi Hospital, Jaipur and the liver was transplanted into a 10-year-old boy at the Institute of Liver and Biliary Sciences in Delhi. The second deceased organ donor was a14-year-old girl Radha Rani. She was brought to, Sawai Man Singh (SMS) Hospital, Jaipur on 22nd February 2015, in a critical condition from Sawai Madhopur. She was declared brain dead on 24th February. The girl's grandfather agreed to donate her organs. Radha Rani's kidneys were transplanted into two patients at SMS Hospital while her liver was sent to the Army R & R Hospital in Delhi through a special Indian Air Force helicopter, where it was transplanted into a patient who was the wife of a soldier. State Health Minister Mr. Rajendra Rathore said the kidney transplant was the first-of-its-kind deceased donor organ transplant in a government hospital in Rajasthan. As a mark of respect and token of appreciation for the young girl, Mr. Rathore said that the Post-Transplant Ward at SMS Hospital would be named after Radha Rani. He had earlier launched a web registry on 6th December 2014, which had consolidated information on patients in need of organ transplant, at a meeting organised by MOHAN Foundation at SMS Medical College.

'Green corridors' in Delhi and Gurgaon enable lifesaving transplants

On 4th January 2015 the Delhi and Gurgaon police came together to create a 32 km 'green corridor' from Fortis Memorial Research Centre (FMRI), in Gurgaon to Fortis Escorts Heart Institute, Okhla in south Delhi. This enabled a convoy of traffic police and ambulance to cover the distance in 29 minutes flat and transport a heart for transplantation into a 16-year-old boy. The urgency was because the human heart has to be transplanted within four hours of retrieval.

The donor was a 30-year-old IT professional who was declared brain dead around 8.48 am on 4th January 2015 at FMRI. According to Dr Avnish Seth, director of Fortis Organ Retrieval and Transplant (FORT), the young man had suffered a stroke on 30th December 2014 that led to his brain death. His parents, who were called from Hyderabad, consented to donating his organs – kidneys, liver, heart and corneas.

Doctors retrieved the heart, as well as other organs for donation, at 3.30 pm and the heart was loaded into an ambulance. "We had conducted a dry run with FMRI last August. As soon as the request for transportation of the organ was received, we contacted our counterparts in Delhi and first decided on the shortest possible route. A pilot gypsy and bike-borne personnel were deployed to clear the route for the ambulance," said Navdeep Singh Virk, the Gurgaon police commissioner. "All traffic signals were put on manual mode and the ambulance was allowed to run signal-free," said Muktesh Chander, Special Commissioner of Police (Traffic), Delhi.

On the night of 17th February 2015, the Delhi Traffic Police created yet another 25 km 'green corridor' to facilitate donation from the oldest deceased donor at AIIMS Trauma Centre. The donor was a 77-year-old man, Vir Bhan Choudhury, a retired Delhi government school teacher. The police cleared traffic and helped in the transportation of the body from Orchid hospital in Janakpuri to the AIIMS Trauma Centre in just about 20 minutes. "The representatives from Dadhichi Deh Daan Samiti contacted us and convinced us for organ donation," said Prem Makkar, son-in-law of the donor. "The body was taken to the operation theatre at 9:30 am on 18th February for retrieval of organs. The body was handed over to the family at 1:30 pm," said Rajeev Maikhuri, organ transplant coordinator, Organ Retrieval Banking Organisation, AIIMS. This was the fifth deceased donation at AIIMS this year. The liver was transplanted to a 30-year-old man at the Institute of Liver and Biliary Sciences, Delhi. The kidneys were transplanted to 48-year-old and 50-year-old male patients at AIIMS. The corneas were also retrieved.

First Successful Hand Transplant in India

India's first hand transplant was carried out successfully at the Amrita Institute of Medical Sciences, Kochi, on 13th January 2015. More than 100 successful hand transplants have been done for several years (the first hand transplant was done in France). They have been considered to be more cost effective and efficient compared to prosthetic hands, especially in bilateral amputees. So far, hand transplants and other composite tissue allotransplants including the face have been done only in USA, European countries, China and Australia. This is the first hand transplant in a coloured skin population in the world and the first in India.

The hand transplant programme was conceived in Amrita Institute of Medical Sciences three years back. The transplant team was led by Dr. Subramania Iyer, Professor and Chairman of Plastic Surgery. Two patients with bilateral amputations just above the wrist were listed in the Kerala Network for Organ Sharing. Since difficulty was anticipated in getting hands to be donated as it would cause change in the external appearance of the donor, an extensive public awareness campaign was initiated.

One of the waiting recipients was a 30-year-old male who had lost both his hands in a tragic train accident three years back. On 12th January 2015, a 24-year-old male patient was declared brain dead after a bike accident. His family agreed for organ donation including his hands. His blood group matched that of the waiting recipient. The procedure started at 4 AM on Tuesday, 13th January and lasted 16 hours. The hands were retrieved from the brain-dead donor and simultaneously in the adjacent operation theatre the recipient was anesthetised and both his hands were prepared. The donor was fitted with artificial limbs after the retrieval and the body was handed over to the relatives.

The recipient progressed well after the operation. As a part of rehabilitation, movements to the hand – active and passive, day-to-day activities were started under supervision. He was able to move his hands since his own forearm muscles were working to move the fingers. The sensations would start to return in three to four months.

Dr. Sunil Shroff presented award for organ donation awareness

Dr. Sunil Shroff, Managing Trustee, MOHAN Foundation was presented the prestigious K. Venkatanarayana TANKER Foundation Awareness Award by Dr. J. Radhakrishnan, IAS, Principal Secretary, Health and Family Welfare, Government of Tamil Nadu at TANKER Foundation's 22nd Annual Charity & Awards Nite on 25th January 2015. The award was given in recognition of Dr. Shroff's work as founder of MOHAN Foundation and for being a pioneer in India in creating "Awareness on Organ donation" across the country since 1997. The award carried a cheque for Rs. one lakh along with a citation and gold medallion.

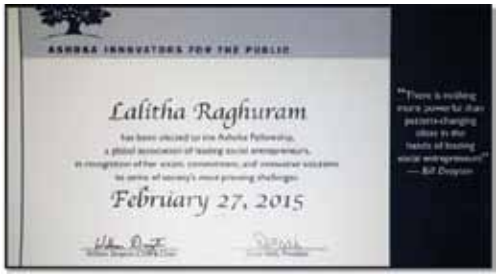
Dr. Shroff accepting the award said that when he started MOHAN Foundation people felt that he had embarked on 'Mission Impossible.' But through perseverance and persistence, it had been proved that deceased organ donation was possible. He said, "This is an award for the team at MOHAN Foundation. The organ donation awareness initiatives have resulted in a paradigm shift in Tamil Nadu, Andhra Pradesh and Kerala with families coming forward on their own to donate the organs of their loved ones." He thanked Dr. Georgi Abraham, Founder, and Ms. Latha Kumaraswami, Managing Trustee, TANKER Foundation for the honour.

Dr. Sunil Shroff (second from left) receiving the K. Venkatanarayana TANKER Awareness award from Dr. J. Radhakrishnan, IAS, Principal Secretary, Health & Family Welfare, Govt. of Tamil Nadu

Mrs. Lalitha Raghuram Inducted as "Ashoka Fellow"

Mrs. Lalitha Raghuram (third from left) with other Ashoka Fellowship awardees at the Induction ceremony in Delhi

Mrs. Lalitha Raghuram, Country Director of MOHAN Foundation was elected as an "Ashoka Fellow" with formal induction on February 27, 2015 in Delhi. Ashoka is one of the largest networks of social entrepreneurs worldwide that recognises individuals that create large-scale impact through new innovations to solve social problems. Mrs. Lalitha Raghuram has played a pivotal role in bringing together all the stakeholders in building a culture of eye and organ donations in India. She is among the 14 social entrepreneurs inducted this year. The two-day induction programme had a series of interactive discussions on how Ashoka can help its Fellows, and also how Ashoka Fellows can leverage on the strengths of Ashoka Global Network. As part of the induction programme, Mrs. Raghuram had a one-on-one interaction with Commodore Ranbir Talwar, Executive Director of Indian Head Injury Foundation, Delhi, to take forward the Swamy Narayan Life Savers' Programme.



Mrs. Lalitha Raghuram, Country Director, MOHAN Foundation awarded Ashoka Fellowship

Dr. Gomathy Narasimhan – India's first woman multi-organ transplant surgeon

Dr. Gomathy Narasimhan

She is a doctor who actually wanted to be an engineer! Gomathy Narasimhan, 41, India's first woman multi-organ transplant surgeon says that in a way she is an engineer of sorts – putting things together and fixing things - in this case the human body. She is presently Senior Consultant, Liver & Kidney Transplant Surgery at Global Hospitals, Chennai.

Gomathy schooled in Chennai for the most part. She studied medicine at Kilpauk Medical College in Chennai where her interest in surgery was kindled. In fact, she topped her class in the subject. But it was only when she was a junior medical officer at the erstwhile Tamilnad Hospital in Chennai that surgery became a passion. The doctors and the environment there enabled great learning and that was where she met her first mentor, Dr. Shanmuga Bhaskar. He was a pioneering transplant surgeon and a man ahead of his time, she said. He encouraged her to push herself, challenge herself. He, unfortunately, passed away in 2007 at the age of 47 because of a malignancy in the kidney.

Gomathy went on to do her post-graduation in Surgery in Madras Medical College, Chennai under the able guidance of Dr. Gunasagaran. Liver transplantation was in its infancy in the late 1990s, but the idea fascinated Gomathy. She did an ASTS (American Society of Transplant Surgery) Fellowship in Abdominal Organ Transplantation (Liver, Kidney, Pancreas) from Baylor University Medical Center, Dallas, USA. She then went to Kumamoto University, Japan to learn the ropes of living donor liver transplant.

She says that the two other great influences were Dr. Georgi Abraham, Nephrologist, Madras Medical Mission, Chennai and her Transplant Fellowship Director in USA, Dr. Edmund Sanchez. From Dr. Abraham she learnt what it meant to be passionate about patient care. Dr. Sanchez, she said, ran the programme with military precision. His take was that the difference between a good surgeon and a great surgeon was attention to detail. Gomathy says that this 'attention to detail' has stood her in good stead, although at the time it felt like never-ending work.

Does she face any gender bias? She is clear that she has never faced it from patients. In fact, she feels that women have an edge over their male counterparts because in the field of transplants it is a longstanding relationship with the recipient. Empathy seems to come more naturally to women and patients seem to find it easier to talk about their personal issues with them.

In the work space, she says that a woman in surgical practice needs to be assertive. There is no quarter asked for or given. One can't afford to be 'weak', either mentally or physically in a field as demanding as transplant surgery. Gomathy keeps fit by doing yoga, swimming and running. She could, literally, give any man a 'run' for his money, after all, she runs marathons!

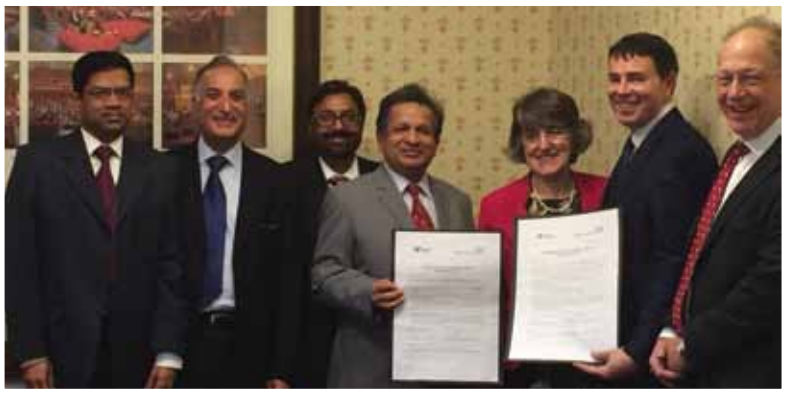
She says that the liver transplant scene in India is extremely promising right now giving hundreds of patients a new life. Through the fellowship programme in liver transplant in her hospital (recognized by the Tamil Nadu Dr. MGR Medical University and the first such programme in India), a number of doctors have been trained and are now junior consultants. She adds that one no longer needs to go abroad to train in transplant surgery. She is also vocal about the need for a transplant registry with good documentation and transplant outcomes. This is extremely essential for public trust and international credibility.

Her newest project is the National Foundation for Liver Research (NFLR), in which she is a trustee along with her colleagues at the Global Hospitals, Chennai – Dr. Priya Ramachandran and Dr. Naresh Shanmugam. The founder trustee of NFLR is Prof. Mohamed Rela. It was launched in March 2014 with the objectives of promoting scientific research in liver disease, improving public awareness about organ donation and expanding access to lifesaving liver surgery for patients irrespective of their economic background.

What's next on her calendar, we ask. Yet another gruelling liver transplant surgery lined up? She says, "No, I'm running the Pinkathon for Breast Cancer Awareness!"

– Dr. Sumana Navin

Stop Press! Dr. Gomathy Narasimhan (second from right) at the Pinkathon in Chennai in April 2014



At the House of Lords (L to R) Dr. N. Sridhar, Dr. Satya V Sharma, MBE, Mr. Mohan Mahal, Dr. Sunil Shroff, Baroness Finlay of Llandaff, Mr. Ian Trenholm, Prof. James Neuberger

Dr. N. Sridhar, Senior Consultant, ICU, Kauvery Hospital, Chennai talking on Donor Optimisation

Prof. James N
Organ Donati
Dr. Sunil Shro
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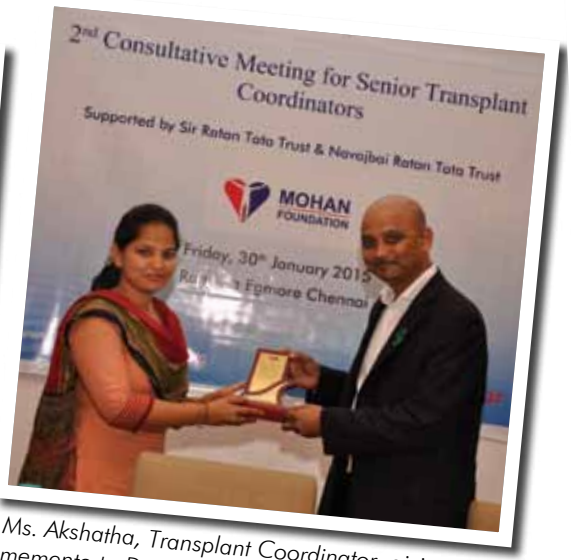
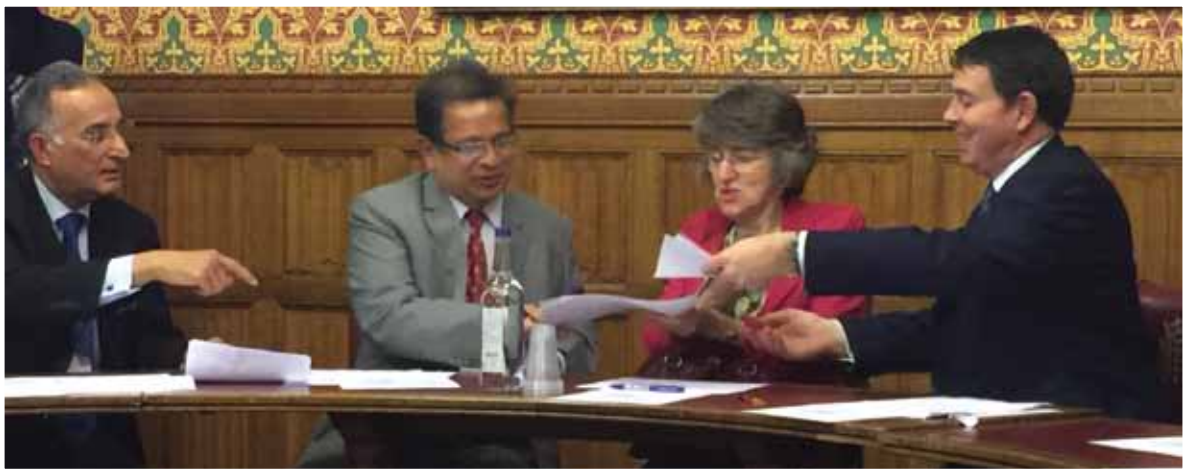
Dr. Nagesh N.S., BMC & RI Super Speciality Hospital, Bengaluru releasing the Indian Transplant Newsletter with Dr. Sumana Navin, Editor



Ms. Akshatha, Transplant Coordinator, giving a memento to Dr. Sonal Asthana, Liver Transplant surgeon, BGS Global Hospital, Bengaluru



MoU signing at the House of Lords, London – Dr. Sunil Shroff, Managing Trustee, MOHAN Foundation and Mr. Ian Trenholm, Chief Executive, NHSBT

Dr. Sunil Shroff addressing the
London

NHSBT MoU

MOHAN Foundation signed a landmark MoU with NHS Blood and Transplant, UK at the Advanced Workshop (2nd consultative meeting) for senior transplant coordinators on 30th January 2015 in Chennai. The MoU was reaffirmed at the House of Lords in London, UK on 26th February 2015. Glimpses of the events are captured in this photo spread.

Dignitaries at the MoU signing in Chennai (L to R) Dr. N. Sridhar, Dr. Satya V Sharma, MBE, Dr. J. Radhakrishnan, IAS, Prof. James Neuberger, Dr. Sunil Shroff, Dr. Chris Barry

euberger, Associate Medical Director for
on & Transplantation, NHSBT, UK and
ff, Managing Trustee,
ndation signing the MoU in Chennai

Dr. Vijayanand Palaniswamy, Adult and Paediatric Intensivist, GKNM Hospital, Coimbatore, explaining the Fallacies in declaring brain death

Dr. J. Radhakrishnan, IAS, Principal Secretary, Health & Family Welfare, Govt. of Tamil Nadu speaking at the MoU signing ceremony in Chennai

Ms. Sunitha A.T., Transplant Coordinator speaking about the Rajiv Gandhi Government General Hospital, Chennai experience

gathering at the House of Lords,

Senior transplant coordinators, faculty and guests at the MoU signing ceremony, Chennai

One Week Transplant Coordinators' Training Programme held in Mumbai

Dr. Jatin Kothari, Consultant Nephrologist, speaking on chronic kidney disease

The 17th one week Transplant Coordinators' Training Programme was held from 8th to 12th December 2014 at KEM Hospital (CVTS Building), Mumbai. It was organised by MOHAN Foundation in collaboration with ZTCC (Zonal Transplant Coordination Centre, Mumbai). There were 34 participants from various parts of Maharashtra and Gujarat. A kidney transplant recipient and the parents of a heart transplant recipient were also there to learn and support the cause.

At the inaugural function, Dr. Shubangi Parkar, Dean, KEM Hospital, said that deceased organ donation was the ideal way to help people. She also appreciated the work being done by MOHAN Foundation. Mr. Bapu Patwardhan, a volunteer of ZTCC who had participated in the Transplant Coordinators' Training Programme in November 2013 in Mumbai, recited a couplet in Urdu - "His lips will no longer smile, but he will bring smiles to many others – that is the supreme achievement of a brain dead person." Dr. Sujata Patwardhan, General Secretary, ZTCC, and the MOHAN Foundation faculty were present on the occasion.

There were lucid presentations on the medical aspects of organ donation and transplantation by Dr. Harshad Purandare, Dr. Shruthi Tandan, Dr. N. K. Hase, Dr. Jatin Kothari, Dr. Viswanath Billa, Dr. Chhaya Shinde, Dr. Aabha Nagral, Dr. Ravi Mohanka and Dr. Madhuri Mahendrakar. Dr. Sanjay Nagral led an extremely interesting debate on the ethics of organ donation and transplantation. Dr. Rajesh Dere's session on handling medico-legal cases and post-mortem drew a lot of questions from the participants given that most deceased organ donors are road traffic accident victims. Dr. Sunil Keswani's session on skin donation was motivating – from April to November 2014 there were 182 skin donations at the National Burns Centre, Mumbai. Dr. Ganesh Sanap gave valuable information about a not-for-profit swap registry called ASTRA. Dr. Kailash Jawade, KEM Hospital presented an interesting study – "Impact of systematic approach to promote cadaveric organ donation in public Institute: Pilot study."

The MOHAN Foundation faculty shared moving donor stories, grief counseling, life skills for a transplant coordinator, the legal aspects of organ donation and transplantation, establishment of a deceased donation programme in a hospital, the successful experience in the Rajiv Gandhi Government General Hospital in Chennai, role of public education and social media in organ donation. Transplant coordinators from various hospitals in Mumbai presented case studies. They discussed on-the-ground challenges and the ways of tackling it. Mr. Anirudha Kulkarni, Ms. Sujata Nadar, Dr. Rekha Barot and Mr. Santosh Sorate spoke extremely articulately giving valuable inputs to the participants. Ms. Sujata Ashtekar spoke on public awareness and the special campaigns undertaken in Mumbai. Dr. B. C. Kempipatil, Dr. Sujata Patwardhan, and Dr. S.K. Mathur elaborated on the role of ZTCC and MCFOT (Maharashtra Confederation for Organ Transplantation). Following a post training evaluation, certificates were handed over to the participants at the valedictory session.

Participants and faculty at the Valedictory Function in KEM Hospital, Mumbai

One Week Transplant Coordinators' Training Programme held in Cuttack, Odisha

The 18th one week Transplant Coordinators' Training Programme was held at the Department of Nephrology, Urology and Renal Transplant Unit, SCB Medical College & Hospital, Cuttack, Odisha from 16th to 20th February 2015. There were 18 participants from Delhi, Kolkata, Jaipur, Bhubaneswar and Cuttack.

At the inauguration, Dr. C. R. Kar, Professor and HOD, Dept. of Nephrology, SCB Medical College welcomed the Chief Guest Prof. P. C. Mohapatra, Dean, SCB Medical College, Dr. D. Hota, Professor and HOD, Dept. of Urology and Renal Transplantation, the faculty from MOHAN Foundation – Mrs. Lalitha Raghuram, Country Director, Dr. Sumana Navin, Course Director, Mr. Bulu Behera, Transplant coordinator – Mr. T. N. Panda, Founder of the NGO MOTHER (Multi Organ Transplantation, Human & Educational Research), and all the participants. Speaking on the occasion, Dr. D. Hota said that renal transplants were started in SCB Medical College & Hospital in 2012 and were being done successfully for the past three years with the support of the government. Mrs. Lalitha Raghuram said that knowledge was available with MOHAN Foundation and a road map could be created for a deceased donation programme in Odisha. Mr. T. N. Panda was of the opinion that a successful deceased donation programme needed general awareness, procedures, hospital infrastructure and facilities, and government support. The Chief Guest Prof. Mohapatra said that SCB Medical College was shortly planning to start liver transplant and corneal transplant programmes in addition to the already existing renal transplant and bone marrow transplant units. Starting a deceased donation programme would add another feather in the cap of SCB Medical College, he added.

In addition to the faculty from MOHAN Foundation, the faculty also included Dr. Rahul Pandit, Senior Consultant, Intensive Care, Fortis Hospital, Mumbai who spoke extensively about identifying and certifying brain death, the pitfalls, and maintenance of a potential brain dead donor, Dr. D. Hota (Body donation), Dr. C. R. Kar (Kidney disease and kidney transplantation), Prof. P. K. Nanda, Prof. & HOD, Regional Institute of Ophthalmology (Eye donation), Dr. Nisith Kumar Mohanty, Consultant Nephrologist, Apollo Hospitals (Immunosuppression), Dr. Mihir Kumar Mohapatra, HOD, Surgical Gastroenterology, SCB Medical College (Liver transplantation), Dr. Braja Kishore Dash, Associate Prof. Forensic Medicine, SCB Medical College (Post-mortem & medicolegal issues), and Mr. Subrat Kumar Sahoo, Transplant coordinator, Apollo Hospitals (Role of recipient coordinator). The other legal, socio-cultural, ethical aspects of organ donation and transplantation, logistics, transplant registry were covered as well as detailed sessions on counseling donor families. A number of films on various topics were also shown to reinforce concepts.

At the valedictory session, Dr. Mishra, Senior administrator, SCB Medical College & Hospital said that it was team work that paid off in any endeavour and that both Dr. Hota and Dr. Kar were team players. They had made a success of the living donation renal transplant programme in a government hospital and the first step in the deceased organ donation programme had been taken with the holding of the Transplant Coordinators' Training Programme. Dr. Mishra presented the completion certificates to the participants.

(Left to right) Dr. C.R. Kar, Dr. Rahul Pandit, Dr. D. Hota, Mrs. Lalitha Raghuram and Dr. Sumana Navin

Participants and faculty with Dr. Mishra (third from right), Senior administrator, SCB Medical College & Hospital at the valedictory function

All smiles! Team members displaying their prize-winning poster

Prof. P. K. Nanda speaking about Hospital Cornea Retrieval Programme (HCRP)

Kidney Disease – Coming FULL CIRCLE: A Patient's View

Mrs. Malathi Venkatesan

For the last 3-4 decades we have been flooded with so much information on kidney disease – the cause for kidney disease, treatment, statistics of how many are affected and how many people have access to treatment because of exorbitant cost and non-availability of facility in many places, success rate in the treatment, awareness about the disease, screening for early detection, conferences on shedding new light on this deadly disease and all the ongoing research being done to conquer the disease. Yet the main question remains unanswered, can kidney disease be completely cured, can a patient become normal and totally released from the clutches of this debilitating disease?

Kidney disease affects a person physically, mentally and financially. It has various kinds of treatment, but you could finally end up where you started – coming FULL CIRCLE.

My Personal Experience

I was a very normal person and led a very simple life with healthy habits. But towards the end of my pregnancy I developed hypertension. Delivery was hastened by two weeks, but it was a normal delivery. After three months the blood pressure (BP) settled down without any medication. After many years as my menstrual cycle was erratic, I was given some hormones to regularise the cycle, which had a bad effect on my BP. So various tests were taken to check the kidney function and all were normal.

A few years later, I had sciatica (pain in my leg) and so took Ayurvedic treatment. During the course of the treatment, protein was found in the urine. So I was referred to a nephrologist and blood tests were done to determine the function of the kidneys. Both urea and creatinine levels were slightly elevated. That was the beginning of my kidney disease. My doctor A. J. Kripalani said, "Only 33% of your kidneys are working. We can only retard the disease, but cannot arrest it. There is no suitable medication, but you need to restrict your diet." Regular blood tests were done to check urea and creatinine and there was no medication given except a minimal dose for BP and some diet restriction. Like this 4-5 years passed, but slowly there were some changes in the blood report. I was advised to get the fistula (an access to do heamodialysis) done as a preparatory step for dialysis. After a year I developed evening rise in temperature and was empirically treated for tuberculosis (TB) for nine months. The fever did not abate even after nine months of TB treatment. I was in Mumbai at that time.

I came to Chennai to take a second opinion about this fever and was told by the doctor that once dialysis is started the fever may subside, as the toxins may be causing the rise in temperature. The outcome of this was that I was started on dialysis, though the parameters and renal profile did not warrant, at that stage, to begin dialysis (it happened to be just guesswork, for the temperature still continued even when dialysis was started).

So this was my FIRST mode of treatment – Haemodialysis (HD). I went through haemodialysis for a few weeks, three times a week. Then I was referred to Dr. Georgi Abraham, a senior nephrologist. After a few weeks of HD, he advised me to go on Continuous Ambulatory Peritoneal Dialysis (CAPD). So my SECOND mode of treatment, CAPD was started. This method is more effective as it is done all day, except at night, and on all seven days. So it is almost like normal kidney function to remove the waste products and balance electrolytes and water, as against HD which is done only four hours a day, three times a week. In CAPD your diet restriction is relaxed, you do this procedure at home without going to the hospital and getting hooked to the dialysis machine. A catheter is inserted into the abdominal cavity and the peritoneum (membrane lining the abdominal cavity) acts as a filter much like the dialyzer in HD. I had to do four exchanges and at night after draining leave it dry. This I managed to do myself as a lot of care has to be taken regarding hygiene to prevent infection going from the catheter into the peritoneum. So this method went on for a few months. I could not travel as I had to carry voluminous dialysate and wherever I went I had to be back home within four hours to do the next exchange. One day, I had very excruciating pain in the upper abdomen with vomiting. I was admitted in the hospital and it was found to be a strangulated umbilical hernia. This was due to pressure of the dialysate fluid in my abdomen, said the doctor, and it had to be operated immediately as gangrene had developed. So I was operated as an emergency and a few centimetres of the intestine were removed. I was back on HD for two weeks till the wound in the abdomen healed. Due to the surgery my haemoglobin level plummeted to 5 (normal 12 – 15.5 g/dl). Then I went back to CAPD. After a few months, I developed pain in my abdomen and vomiting. It was unmistakably another hernia again. I was operated and this time they put a mesh around that area to prevent recurrence.

My doctors now said that I should consider transplant as a solution to the problem. Meanwhile when routine serology test was done it was found that I had become HCV positive (via the dialysis machines). This was an unexpected development. So transplant could not be considered with this problem, as the infection could flare up when immunosuppressant was given after the transplant. So I was given treatment with a medicine called Interferon. I had a violent reaction to it with very high fever, body pain, extreme exhaustion and frequent hospital admissions. Since I could not tolerate it, the

medicine was withdrawn. Meanwhile the low grade fever I'd had for two years still continued. So I was advised by my doctor to consult an immunologist in Vellore about this fever. There the doctor did various tests and assured me that the fever of unknown origin would not interfere or affect the outcome of transplant. This was a strong assurance that we could proceed with transplant. Finally my blood sample was sent to Singapore to be tested for HCV. The result declared that the HCV was dormant. So the transplant could be scheduled finally.

My third mode of treatment was a TRANSPLANT. With all the tests done and matched with my donor kidney (my cousin) the transplant was done on 19th May 1995. All went well. The output of urine was excellent and creatinine plunged from 8.5 to 0.6. I was discharged after two weeks and had to do regular routine checks for kidney functioning. For the next three months there were very strict rules to prevent infection. No going to crowded places, restriction on visitors, very stringent method of preparing food and serving, measurement of urine output etc. – all had to be strictly followed. All along my mother, my husband and daughter and my brother were of tremendous support to me to fight this disease. I stayed in a very sprawling bungalow, which was the guest house of my husband's company during my convalescence. It was full of greenery and pollution free clean air. I am very grateful to the company for allowing me to stay there. This helped me to recoup fast. I returned to Mumbai and was very normal within the restricted frame work, which I had to observe both in diet and avoiding infection.

The next few years were very smooth and I resumed my normal activities. My daughter's marriage took place two years after my transplant and I was able to perform it with lots of energy and strength. I started travelling to many places without worrying about dialysis and post-transplant precautions. Life was smooth sailing for almost 18 years after the transplant and I almost forgot about my illness.

In 2010, 15 years after transplant I started getting UTI (Urinary Tract Infection) often. I was admitted in the hospital frequently and given heavy doses of antibiotics for two weeks or so. The doctor felt that the transplanted kidney was getting rejected slowly and the UTI infection must have infected the kidney also. In 2012, one day I felt very breathless with pain in the chest and gasping. I was admitted in the Cardiac ICU. An angiogram was done, which revealed a block in one of the blood vessels. A stent was put in as it was felt that a bypass would be risky. Till now the stent is working well in spite of many episodes of very high BP and potassium levels. In 2013, my legs started to swell and I was not energetic. The doctor advised me to get the fistula done again; to be prepared in case the need arises. This upset me a lot for I knew that my transplanted kidney was slowly giving way and rejection had started. So a fistula was done again. By middle of June, my BP was uncontrollably high and did not respond to any medicine. Dialysis was started and I was once again hooked to the machine from July 2013. This went on smoothly for some time. But then one morning in August, I had severe pain in both my legs and could not even get up from bed or turn from side to side. The investigations revealed nothing and the cause of the intense pain was a medical mystery. With all this I had dialysis three times, which was a challenge with severe leg pain.

Then came the worst period when I developed an abscess in my left groin. The abscess turned out to be much deeper than first thought. After it was operated on, the cleaning deep inside the raw wound every day was a nightmare. When I asked about this infection, the doctor said it may be due to long period of immunosuppression (18 years). It is so ironic that the medicine given to prevent rejection led to another terrible problem as its side effect. I understood that patients not only have to handle the disease, but also the added problems caused by medication. When this settled, I started to get breathless in the night. Thrice at night I had to be rushed to the hospital. There was not much weight gain, but BP was very high. Every time they also checked the potassium level. It was very elevated. Once I was rushed and the potassium was 9.2 and the pulse was 14. The doctor said they had not seen a patient surviving with such a high level of potassium! These episodes of very high potassium continued and the doctor felt that I was under-dialysed. So I started undergoing dialysis four times a week. Even with this the potassium and BP did not settle down for many weeks. Finally it was found that the fistula had failed. This was a big shock. All along it appears the blood in the dialysis machine was inadequate. This meant I was inadequately dialysed and this was the main reason for high level of potassium, in spite of being dialysed four times a week. Because of this oversight I suffered for three months, frequently visiting the hospital at all odd hours with high potassium and BP without knowing the cause.

Since the fistula failed, a Permacath (in the chest) was put in as an access for dialysis. The potassium level came down within three days and the BP also settled down. Now the dialysis is going well, but I feel irked due to the itching because of the plasters on the skin around the catheter, pricking pain, sensitive skin, which sometimes bleeds. The Permacath should not get wet and so normal bath also cannot be taken. Due to this my very favourite exercise swimming was totally stopped, which is very frustrating.

So now I am back on dialysis and have come FULL CIRCLE having gone through Haemodialysis, CAPD, Transplant, rejection of the kidney, access failing and in the process all the accompanying trauma of infections, frequent hospital visits, prolonged stay for the last one-and-a half years. YET I FIND NO CURE OR RESPITE OR FREEDOM FROM THIS DEADLY DISEASE. Our only hope lies in medical research in this major area to prevent rejection, which will be a great step to conquer this deadly disease.

Editor's note – Mrs. Malathi Venkatesan is on the Board of Trustees of MOHAN Foundation and TANKER Foundation, Chennai. She has been selflessly guiding and mentoring both organisations for many years. The setbacks in her health have not stopped her from helping organ failure patients and supporting the cause of organ donation.

Deceased Donation Statistics

Deceased Organ Donation Statistics – 2014

State	No. of Donors	*ODR (pmp)	Kidney	Liver	Heart	Lung	Pancreas	Intestine	Total Organs
Tamil Nadu	136	1.9	227	129	41	15	4	1	417
Kerala	58	1.7	104	44	6	0	0	0	154
Maharashtra	52	0.5	89	43	0	0	0	0	132
Andhra Pradesh	52	0.6	92	54	1	1	0	0	148
Karnataka	39	0.6	72	37	5	0	0	0	114
Gujarat	28	0.5	55	25	0	0	0	0	80
Delhi-NCR	20	1.2	32	18	0	0	0	0	50
Puducherry	13	10.4	26	0	0	0	0	0	26
Uttar Pradesh	7	0.04	14	0	0	0	0	0	14
Chandigarh	6	5.7	9	4	1	0	1	0	15
Total	**411**	**0.34	**720**	**354**	**54**	**16**	**5**	**1**	**1150**

*ODR (pmp) – Organ Donation Rate (per million population)
**0.34 – National Organ Donation Rate

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