

# INDIAN TRANSPLANT NEWSLETTER

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**MOHAN FOUNDATION**

MULTI ORGAN HARVESTING AID NETWORK

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**Editorial Desk****Improving Organ Donation Rates Among Asian Indians In the UK & USA**

The high kidney failure rate among the Asians from the Indian sub-continent and their low donation rate has meant that these communities wait longer to get a kidney transplant in countries such as USA & UK, where there is a large population from the sub-continent. The desperation of waiting longer sometimes results in them seeking a paid donation in their home country.

To address the issue MOHAN USA (a charity with 501 C status in the USA) in association with American Society of Transplant (AST), organized a focussed conference in Seattle on 2nd of June 2018 with the theme 'Strategies to Increase Awareness and Organ Donation Rates Amongst Minorities.' The meeting was moderated by Dr. Anil Chandraker, Past President of the AST.

MOHAN Foundation in India through the placement of trained transplant coordinators in government hospitals in three states - Tamil Nadu, Telangana and Rajasthan has shown that the consent rate of a potential brain dead donor to be over 65% when the family is supported in their decision to donate by a trained coordinator. Similar conversion rate has also been seen across the country in many other programs where their trained coordinators have been employed by various hospitals. However, this conversion has not been achieved in countries like the United Kingdom or United states of America among the Indian population.

In the UK Black, Asian and minority ethnic (BAME) groups represent 11% of the UK population of which Asians represent 5.1% of the population while 2.5% of the population are Black and 3.2% are from other minority ethnic groups. At the end of the 2017/18 financial year, 35% of the total number of patients on the waiting list for a kidney transplant were from BAME group, reflecting a demand for kidney transplantation in excess of that for White patients. There are currently 6,871 people on the transplant list, including 1071 British Asian people. Recent data from 2017-18 show that only about 40% of such eligible donors from BAME support organ donation compared with about 70% from the whites (1)



Dr. Clive Callendar receiving a plaque after his keynote address from Dr. Sunil Shroff along with Dr. Anil Chandraker

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## Workshop on Deceased Donation for ICU & Transplant Coordinators organised in Kathmandu, Nepal



The Prime Minister of Nepal Mr. K. P. Oli (seated centre) during a session at the 1st Conference of Nepal Transplantation Society and 11th Conference of Nephrology, Urology and Transplantation Society of SAARC

For the first time in Nepal, a Workshop on Deceased Donation for ICU & Transplant Coordinators was organised by MOHAN Foundation and Nepal Transplantation Society (NTS) on 25th & 26th April 2018 at Hotel Radisson in Kathmandu. Over 75 ICU doctors and nurses attended the workshop. This was a pre-conference workshop of the 1st International Conference of NTS and 11th Nephrology, Urology & Transplantation Conference of SAARC. Nepal has recognised brain death as a form of death and is ready to embark on deceased organ donation and transplantation. This workshop will go a long way in promoting deceased donation as all the key stakeholders participated in the programme. The Prime Minister of Nepal, Mr. K. P. Oli, too is keen to promote this form of donation.

Dr. Bhola Raj Joshi, President NTS in his welcome address said that the workshop would help ICU staff understand how to improve the donor pool. Dr. Dibya Singh Shah in her 'Overview of transplantation in Nepal' said that the first successful living related kidney transplant was performed at Tribhuvan University Teaching Hospital in August 2008. In 2017, 300 kidney transplants were performed in the country. At present, there are 3000 patients on dialysis. Dr. Subhash Acharya outlined the Human Body Organ Transplant Act, 1998, the Kidney Transplant regulations of 2002, and the amendments in 2016 (brain death, provision for paired exchange, wide expansion of list of immediate relatives for live donation). He explained that all guidelines have been given regarding certification of brain death. The other faculty from Nepal were Dr. Gentle Sunder Shrestha, Dr. Pramesh Shrestha, and Dr. Gopal Kumar Chaudhary who gave their valuable inputs on the medical and medicolegal aspects of deceased organ donation.

The faculty from India included Dr. Kapil Zirpe, Head of the Department of Neurocritical Care, Ruby Hall Clinic, Grant Medical Foundation, Pune, India and the current President of the Indian Society of Critical Care Medicine (ISCCM), Dr. Subhal Dixit, Director, Critical Care, Sanjeevan and MJM Hospital, Pune and President-elect of ISCCM, and Dr. Avnish Seth, Director, Gastroenterology & Hepatobiliary Sciences and Director, Fortis Organ Retrieval and Transplant, FMRI, Gurgaon.

The faculty from MOHAN Foundation included Dr. Sunil Shroff, Managing Trustee, Dr. Sumana Navin, Course Director, Ms. Pallavi Kumar, Executive Director Delhi NCR and Ms. Sujatha Suriyamoorthi, MIS and Programme Manager. The whole team shared the learnings and continuing challenges in India as well as possible takeaways for Nepal.

The panel discussion on 'How to create an organ sharing registry and give momentum to the deceased donation programme in Nepal' was moderated by Dr. Sunil Shroff. The panelists were Dr. Pawan Chalise, Dr. Prabin Adhikary, Dr. Diptesh Aryal, Dr. Amit Sharma Bhattarai, Journalists Kalpana Acharya and Bhagvati Timal Sinha, Raj Kumar Silwal – DSP, CIB, Bimal Basnet - SP, Police HQ Kathmandu, and Dr. Avnish Seth. At the end of the discussion, the panelists shared their thoughts on what they felt were the key areas: Dr. Pawan Chalise – clarify legal framework to facilitate deceased donation, Dr. Prabin Adhikary – all stakeholders need to be onboard, formulate a committee for organ donation, Dr. Diptesh Aryal – identify champion nurses and train them, Dr. Amit Sharma Bhattarai – consider having opt-out system, Kalpana Acharya – media plays a major role and can be a bridge to reach ordinary people, Bhagvati Timal Sinha – media will support the cause and the police should observe the process minutely, Raj Kumar Silwal – educate people and start the deceased donation discourse in Nepal, Bimal Basnet – donation is very important in Hinduism, campaign for awareness first within the family, then society and country, Dr. Avnish Seth – focus needs to be on converting potential donors to actual deceased donors.



Faculty and participants at the Deceased Donation Workshop

...continued on page 5

## An 18-hour transplant results in three lives being transformed in Bengaluru

Three patients got a fresh lease of life when doctors performed a triple transplant of heart, liver and kidney simultaneously on the night of 3rd June 2018. The doctors of Manipal Hospitals on Old Airport Road took nearly 18 hours to complete the three procedures. The donor of all three organs was a 32-year-old woman from Kolar, the daughter of a construction worker who died after a fall. According to the in-house priority and organ donation protocol, all three vital organs were allocated to Manipal Hospitals as it had matching registered recipients.

Dr. Vishwanath Siddini, consultant nephrologist, said the kidney recipient had diabetes and was on regular dialysis for nearly four years. He said, "It was a challenging task to perform the transplants as the three major procedures done simultaneously involved a team of 100, including doctors." Consultant cardiothoracic and vascular surgeon Dr. Devananda said the heart recipient was suffering from dilated cardiomyopathy and underwent a month's preparation before undergoing the heart transplant. Dr. A. Olithselvan, chairman and hepatologist, Liver Transplant Division, Manipal Hospitals, said the 60-year liver recipient had been fighting liver cancer for the past three months and liver cirrhosis for almost six years.

## Transplant Games 2018 organised by PGIMER, Chandigarh

The Transplant Games 2018 were organised by the Department of Renal Transplant Surgery, Postgraduate Institute of Medical Education and Research (PGIMER) and Organ Transplantation Trust. More than 500 transplant recipients and donor families from across the country participated in the games. "Chandigarh has the proud distinction of having a rate of 41 per million population matching even the international standards, all due to PGI's consistently successful cadaver donation programme," said Professor Jagat Ram, Director, PGIMER.

Professor Ashish Sharma, head, Department of Renal Transplant Surgery said, "The spirit of the Transplant Games is to demonstrate success of organ transplantation. Many patients with organ failure previously may not have been able to engage in any sort of sporting activity due to their illness. But the gift of organ donation enables these patients to maintain a normal lifestyle and live their life to the fullest." The Transplant Games 2018 had several activities including cricket and badminton matches, fast and furious sprints and races, tug of war and intense and invigorating carrom matches. There were rangoli and poster making competitions also to showcase the artistic and creative potential of the participants, said officials.

## Heart flown from Jaipur to Delhi gives a new lease of life

A heart transplant conducted within three hours of harvesting the heart from a donor in Jaipur helped a 56-year-old patient get a new lease of life in Delhi. "The patient is recovering well after the successful transplant," said Dr Ajay Kaul, Chairman and Head of Department, Cardiothoracic and Vascular Surgery (CTVS), BLK Super Speciality Hospital.

He led the team of doctors who harvested the heart and transplanted it. The patient, a government employee from Kanauni village of Ghaziabad had been suffering from dilated cardiomyopathy. The heart transplant became possible because of the organ donation from a 30-year-old male from Jaipur, who was declared brain-dead at SMS Hospital in Jaipur following a road accident. While the kidneys and eyes were used in Jaipur, the liver and heart were sent to Delhi. The doctors at BLK Super Speciality Hospital swung into action when National Organ and Tissue Transplant Organisation (NOTTO) informed them about the donor and availability of a heart. Dr. Kaul and his team left for Jaipur by an early morning flight and harvested the heart at night. They landed in Delhi at 10.47 pm. A green corridor was created from IGI Airport to BLK Super Speciality Hospital covering a distance of 15 km in just over 18 minutes at night. The heart was transplanted late into the night.

## Youths turn saviours, breathe life into India's organ donation drive

Fifteen-year-old Mumbai resident Vaibhav Sanghavi had just completed his Class X exams in 2016 when he was asked a question that is rarely asked of someone so young: Would he consent to donate the organs of his 44-year-old mother who had just been declared brain dead? As their father was long dead, it was left to Vaibhav and younger brother Ravi to decide. They answered in the affirmative, proving what experts always say about the willingness of today's youth to accept and promote the otherwise ignored theme of organ donation in India. The boys attended all the meetings and seminars on organ donation that they were invited to, unofficially earning the title ambassadors of organ donation in the Maharashtra circle. "Youngsters can motivate other family members. They are instrumental in making decisions as far as organ donation is concerned," said Dr. S. K. Mathur of the Mumbai Zonal Transplant Coordination Centre (ZTCC).

There is no nationwide study of age profiles of Indian deceased donors, but doctors say that the youth and the aged form the biggest groups of donors. The reason for this is not hard to find. Road traffic accidents and intracranial bleed are the two main causes of brain death, which is a precursor for cadaveric organ donations.

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Sd/-

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## A Pathbreaker in Pune – Mrs. Arati Gokhale, Central Coordinator, ZTCC - Pune



Mrs. Arati Gokhale

Mrs. Arati Gokhale's pathbreaking efforts have put Pune on the map of deceased organ donation in India. As Central Coordinator, Zonal Transplant Coordination Center (ZTCC)-Pune, Arati has tackled many challenges successfully. She learnt to face challenges head-on right after she completed her Masters in Social Work from Karve Institute and started her career as a social worker in Ruby Hall Clinic, Pune. When she began working, there wasn't even a separate room for counselling. But in spite of that Arati counselled HIV positive patients and their families, suicidal students, and patients in ICU with sensitivity and patience. On one such occasion, the Founder - Chairman of Ruby Hall Clinic, Dr. K. B. Grant happened to witness her interaction with a patient. He was so impressed that he made provision for a space for counselling.

In 1993 Ruby Hall Clinic started an eye bank. Arati took up this new challenge and began creating awareness and counselling families who had lost a relative for eye donation. In 1994, when the law regulating living and deceased organ donation and transplantation came into being in India, Arati decided to get involved in the field. It was not an easy task, but Arati was not the kind of person who said 'no' to a challenge. She armed herself with the necessary knowledge to be able to counsel patients with kidney failure and their families. She spent time observing Dr. A. G. Huprikar, Nephrologist (and currently Secretary, ZTCC-Pune) at work in the Out-Patient Department, and learning the ins-and-outs of chronic kidney disease and kidney transplantation. Arati's thirst for knowledge took her to TPM-DTI in Barcelona, Spain where she underwent a Diploma in Organ Procurement in 2002. Based on the volume of work that Arati had done, she was offered a scholarship for the training and received sponsorship for travel and other expenses. In fact, she was the only person to be offered the scholarship out of 52 students coming from different nations! Arati came back inspired from Barcelona, but there were no organ donations for three consecutive years. Yet, she did not lose heart.



ZTCC-Pune came into being as a non-governmental organisation in the field of organ donation in 2004, but its work started in a concerted manner almost 10 years later. Arati joined ZTCC-Pune in September 2013. Recognising the need for an organ allocation system, she worked on creating consolidated waiting lists of patients with organ failure. Also, ZTCC-Pune started organising more awareness campaigns for the general public and training programmes for the medical fraternity and transplant coordinators in collaboration with the Indian Medical Association, Indian Society of Critical Care Medicine, National Organ and Tissue Transplant Organisation, and MOHAN Foundation. Arati gives credit to the managing committee of ZTCC-Pune for taking an active part in all the activities and playing a very important role in implementing policies. One such pathbreaking activity was a film 'Phir Zindagi' (Life Continues) based on the concept of deceased organ donation for which Arati gave key inputs. It starred eminent actors Ratna Pathak Shah, Naseeruddin Shah and Neeraj Kabi who brought the concept to life. It has moved many a member of the audience to tears wherever it has been screened.

As central coordinator Arati is responsible for fair and equitable distribution of organs, organising 'green corridors' to facilitate speedy transport of organs, coordinating with various stakeholders (transplant coordinators, doctors from various hospitals with different specialities), and completing this task in a limited timeframe. Keeping one's balance and maintaining neutrality is very difficult in such situations, but Arati pulls it off admirably.

The transplant coordinators' training programme has been successfully organised in Pune, in collaboration with MOHAN Foundation, since 2016. Arati's sessions on her journey as a social worker/coordinator, the early challenges in ZTCC-Pune and the successes, as well as her experiences in organising 'green corridors' – 17 of them in one year, have inspired the participants. In fact, Mr. Sarang Awad, IPS, ACP – Traffic, Pune said that he accorded a 'green corridor' request from ZTCC-Pune the same status as that of a VIP! Arati said that there were 56 deceased organ donors in 2017 from the Pune region. Two hospitals contributed to this in a big way – Ruby Hall Clinic with 21 deceased donors and Sahyadri Hospital with 20 deceased donors. She added that through the unique mobile app (GridSense Health) that had been created for ZTCC-Pune the method of organ allocation had become very efficient. Arati says her goal is to improve the organ donation rate in her region through new initiatives. In the meantime, she has been awarded a scholarship through MOHAN Foundation to attend a Mini Fellowship in Organ Donation offered by the Gift of Life Institute in Philadelphia, USA. Come October 2018, she will be embarking on yet another empowering journey to help her reach her goal.

- Dr. Sumana Navin



## A Cyclone of Thoughts

*Mrs. Surekha Joshi  
Transplant Coordinator and Manager  
Ruby Hall Clinic, Pune*

One fine winter morning, I received a call from our Neuro Trauma Unit. As I entered Dr. Zirpe told me about a 29-year-old young male who was brain dead following an intracerebral bleed. We counselled the relatives and explained about brain death to the family members. They were distant relatives who told us to explain the same to the patient's wife and brother-in-law.

After sometime we explained to the wife (22 yrs) and brother-in-law about organ donation and they agreed for the same. They were very positive and allowed us to take as much time as required for the entire process. But after looking at the brother-in-law my expression changed as he was a transgender.

After completion of written consent of all organs, I informed Zonal Transplant Coordination Centre (ZTCC) Pune for organ allocation. Organs were allocated as per the ZTCC Norms. Lungs were allocated through NOTTO to Chennai. Tentative retrieval timing was 11.30 pm.

At 11 pm, assessment of lungs was in process by Chennai team. The brother-in-law with all his community members, about 15-20 came to me (they were all drunk), and were bargaining. They demanded cash in return for organ donation for the patient's children or job for his wife (it was a love marriage and they were married at a very early age and had three children). I said this was against the law and it was not at all possible, so if they were not ready they could withdraw their consent for organ donation. The brother-in-law told that they wanted to withdraw the consent. Immediately informed the same to ZTCC. I went to the NTU as I received a call from the consultant. I also made a call to our Medical Director (MD) and explained the situation.

Some of the transgenders at the same time went to the NTU where the patient was admitted and threatened the lung assessment team and NTU staff. They were continuously doing video recording. The lung surgeon saw all this, and got frightened and he left. Meantime our MD reached the hospital and asked me to bring the relatives as he wanted to speak to them. As the whole mob entered his office, all security guards also entered the office, and the relatives got violent asking why were the security called. So without having any discussion they went off. Our MD told us to close this case for organ donation immediately; it was at 1 am at night. As I was about to leave the hospital, again the transgender community along with police caught me in the corridor. The PSI (the same PSI who had come to give NOC for another organ donation case three days back), saw me and smiled. He tried to tell the relatives that whatever this madam is doing is according to the law, you have signed the consent for organ donation which is a very valuable decision. But the relatives said that they wanted to file a complaint against me, that I have misguided them and they have the video recording of the same.

Video recording was also done of all the discussion that they had with the police and me. So, the PSI asked them to come in the morning to file a complaint and dramatically he shouted at me. I was confidently answering all the questions of the relatives and PSI, although I was a little bit scared on the inside. But I saw the MD standing behind me throughout this situation, so got relaxed. At 3.30 am I went home, after reaching home I received a message from the MD that there was a meeting in CEO's office at 10.00 am sharp to discuss this case. Even in this tense situation, my family members supported me. My elder daughter suggested that I call Ms. Laxmi, who was the head of the transgender community. She had declared in her interview on TV the previous week that she supported organ donation. In the meeting I explained the case in detail to the CEO. But he was insisting repeatedly to get consent from the family again in front of the police.

As the relatives had filed a complaint against me, the police came for the enquiry. Immediately after that the relatives along with the brother-in-law approached me in MD's office and apologised for the night's incident and said that they wanted to go ahead with organ donation. The relatives withdrew the complaint filed against me and in front of the police they again consented for organ donation.

Meanwhile our heart recipient was medically unfit, so ZTCC offered the heart to Mumbai and lungs were not retrieved.

As every case gives us a lesson, from this case as well I learnt a lot and now am able to face situations confidently while counselling the relatives from any community.

*In the News - International ...Continued from page 2*

## 7-year-old boy becomes first child to undergo five-organ transplant

A 7-year-old boy in the UK has become the first child to undergo a five-organ transplant in one operation. The team at Birmingham Children's Hospital in the West Midlands, UK, operated on Jay Crouch for 10 hours to implant a liver, two kidneys, a pancreas and bowel. Following the surgery in March 2018, Crouch was able to swallow food for the first time in his life. He is now at home, recovering with his family. Crouch was diagnosed with short bowel syndrome when he was six weeks old. The condition caused his small intestine to twist, and triggered complications with his kidneys and other vital organs. As a result, he had never eaten or digested food before the procedure, and was instead fed intravenously throughout his life.

Crouch said in a statement, "I want to say thank you to my mum for looking after me and my grandma and granddad, who have been telling me every day that I'm getting better." Acknowledging her son's deceased organ donor, Katie Freestone said, "There aren't enough words to say thank you to the donor and their family and while we're thrilled that Jay has been given this chance, we're also incredibly aware of the sadness and tragedy that another family had to endure to make this possible." Khalid Sharif, consultant surgeon and lead for transplantation who operated on Crouch, said, "It's incredibly rare for these many organs to be successfully transplanted at once and shows the difference that organ donors make to the lives of others. Without the generosity and selflessness of donors, their families and loved ones, such life-saving procedures simply couldn't take place."



## MOHAN USA in association with the American Society of Transplantation (AST), pioneers the cause of improving Organ Donation Rates Amongst Minorities in the Country



Dr. Anil Chandraker during his presentation

MOHAN USA, in association with American Society of Transplant (AST), organized a special event on the 2nd of June 2018 at Seattle, Washington. The educational event, titled, 'Strategies to Increase Awareness and Organ Donation Rates Amongst Minorities' coincided with the American Transplant Congress, the largest gathering of transplant professionals from all over the world, being held in the same city.

Moderated by Dr. Anil Chandraker, Past President of the AST, the educational event saw a sold-out crowd listen to many speakers present their work on this topic. The opening remarks were delivered by Dr. Anirban Bose, President of MOHAN USA, following which Dr. Sundaram Hariharan enlightened us about the objectives of his organization Transplant Professionals of Indian Origin (TPIO). Ms. Claire Bonilla CEO of SightLife gave a superb talk, bringing into focus, the importance of local cultural sensitivities in the field of organ and tissue donation.

Next to speak was Dr. Clive Callendar, the evening's Keynote Speaker, who delivered an inspirational tale of his life's work, his journey in the founding of the Minority Organ Tissue Transplant Education Program MOTTEP, the hugely successful program to increase donor registration and organ donation amongst the African American community in the US. He was followed by his protégé, Dr. Keith Melancon, Professor of surgery at George Washington University, who enlightened the attendees on the outcomes of organ transplants among minorities.

Next on stage was Dr. Randeep Kashyap, surgical director of Kidney transplant at the University of Rochester, whose research focused on using primary care physician offices as effective enrolment venues for organ donor registration.



Dr. Clive Callendar addressing the gathering

This was followed by an impassioned lecture by Mr. Kevin O'Conner, president and CEO of Life Center Northwest, the most successful Organ Procurement Organization in the country on the key strategies to increase organ donation and registration.

The final presentation was by Dr. Sunil Shroff, founding trustee of MOHAN Foundation, who touched on the salient points about organ donation patterns in South Asia and the local topics and sensitivities that affect it.

### The Impact

A lively debate and discussion ensued at the end of the lectures about potential strategies to increase organ donation amongst minorities, especially South Asians, who have a significant burden of disease, but a low organ donor registration and consent rate. Dr. Callendar's talk was very revealing as the audience learned how the rate of donations among the black population has risen over a decade due to public engagement and creating community awareness by MOTTEP at the grassroots level. Thanks to their work, the latest UNOS data shows that the rate of donation among blacks is either comparable or better than most ethnic groups in the country.

It was also evident that there is very little data in the literature about organ donation and registration rates among the South Asian population. Based on the personal experiences of the experts present at the meeting, it was felt that there is a great need to engage this community in this process and reach out to them at the grassroots level to increase their participation in both organ donation and registration. There was unanimous agreement that it was vitally important to perform more research on this topic and Dr. Callendar and Dr. Melancon offered help with their expertise to MOHAN USA to get in step with the logistics of research.



## Evening Gala: MOHAN USA Fundraiser



Ms. Claire Bonilla being felicitated by Dr. Sunil Shroff with Dr. Anil Chandraker

Immediately following the educational event, an evening gala was organized by MOHAN USA to raise awareness about organ donation and seek funding for their many programs. The evening saw a jam-packed hall with close to a hundred and fifty guests being entertained with live music, dancing and inspirational stories of how organ transplants had affected many lives.

Dr. Anand Vadivel laid the event foundation with his welcome address. Lalitha Raghuram, country director of MOHAN Foundation, began with a soul stirring invocation after which Meghan and Rohan entertained the audience with their sultry, sweet songs. Next to rock the stage was Abha's dance troupe, performing some energetic Bollywood dance numbers, much to the delight of the audience.

Dr. Anirban Bose then addressed the gathering, bringing to focus the importance of the work of MOHAN Foundation. To highlight the Foundation's journey and achievements, he called on Dr. Sunil Shroff to introduce the audience to MOHAN Foundation in more depth. Dr. Shroff's talk was very well received and when he introduced the gathering to two heart transplant recipients: Mr. Ron Lemmer (an American with an Indian heart) and Mr. Mohan Mahal (an Indian with an American Heart) it showed how organ transplant transcends nationalities, ethnicities, religions and brings humanity closer. The crowd broke into spontaneous applause.

The highlight of the evening was the personal story of Lalitha Raghuram, MOHAN Foundation's country director, who has not only 'talked the talk' but also 'walked the walk.' She related the story of how she donated the organs of her son, Swamy, after he suffered a traumatic brain injury and saved the life of Luv Dhody, who received Swamy's liver. Luv Dhody, along with his wife and two daughters, joined Lalitha on stage to underscore the point that organ donation isn't about death... it is about giving new life.

This celebration of LIFE continued with a sumptuous dinner. Two more musical performances by talented guitarist Rohit and singer Moinak, was greatly appreciated by the audience. Abha's dance group returned to perform three more energetic dance numbers to nicely bookend the entertainment section of the evening.

Dr. Anirban Bose, delivered the vote of thanks to express MOHAN USA's appreciation for the hosts, organizers, guests, participants, donors and recipients for their time and effort. Although supported by MOHAN USA, the event wouldn't have been possible without the tireless energy of Dr. Anand Vadivel, Yash and Divya Shroff.



The evening came to a wonderful end with many members of the audience making pledges to donate or seeking ways to participate in helping this noble cause.

- Dr. Anirban Bose

## 'Highest' tribute to Organ Donors and their families at Everest Base Camp



Ms. Pallavi Kumar, Executive Director Delhi-NCR, MOHAN Foundation, undertook a very unique and challenging journey to pay the highest tribute to organ donors and their families.

On May 4, 2018, she summited the Everest Base Camp reaching an altitude of 5380 meters (17600 feet above sea level) and unfurled a flag expressing her respect and thankfulness to the many organ donors and their families.

The trek involved walking 130 kms over 12 days (walking an average of 10 kms every day, some days up to 18 kms). On the day of the summit, it was snowing and temperatures dipped considerably, dropping to -17 degrees. With numb hands & feet and braving icy winds, Pallavi reached the Everest Base Camp and tied the flag sending out a strong message for the need for organ donation.

"The trek involved dealing with cold, exhaustion and high altitude acclimatization. On some days, the oxygen levels were so low that every step fatigued you. It was so tough at times that I questioned my sanity, as to why did I ever decide to do it. But what kept me going was my strong need to reach the top and the inspiration I took from families who have made this tough choice in their hour of grief and loss," said Pallavi.

## Quality in Healthcare: Time to ask the right question?



**Suresh Sankar A.B**

(Int Med, Neph) FRCP, FASN, MBA  
Nephrologist, Chief Medical Officer  
DaVita Kidney Care, India

The health of the people of India and Healthcare in the country are on a positive trajectory despite many challenges.

Intensely debated, optimists quote private health care being on par with global standards and cost amongst the lowest in the world as supportive evidence. Simultaneously, activists, public health professionals call out the inferior status of primary care, dominant out of pocket payment system, poor Insurance coverage, and inadequate regulation, as a bane. However, a persistent blind spot in the evolution story is "health outcome" as a quality measure to assess the quality of healthcare delivery. It answers the question, how good is the health-care provided when measured by improvement in health status

"Health outcome" is what is valued most by patients and family members. We would all want our loved ones to be better, irrespective of where, how and why we seek care. In well-evolved health systems health outcome is an indicator under intense scrutiny by users, policymakers and payers. At a system level, it requires data definition, data aggregation, analysis, metrics, reporting, and dissemination. Health outcome of populations can be compared across regions, providers or trended over time. In the Indian health system, in a broader context, such a core objective of the health system remains in the realm of unknown.

In India, the private healthcare has potential lessons to imbibe from the public health care system. For several decades, public Institutions, state, and central government have been systematically reporting health indicators of population, in globally accepted formats and frequency (to be read as health outcome indicators) like life expectancy, infant mortality rate, maternal mortality rate. It has helped the health system gauge performance of maternal and child care, understand barriers and improve inputs and processes. It is commendable that these indicators have improved significantly despite growth in the volume of services.

Health outcome analysis could be potentially combined with study of the cost incurred to achieve a defined outcome. Such an initiative would dissect "appropriate cost", which are essential to achieving quality versus "excessive or unnecessary cost" which could be wastage or what is often construed as profiteering. We are battling to justify the "cost stretch" in care provision between the judgmental compulsions of medical fraternity often done with the right intentions, and the perception of "excessive and unnecessary diagnostics and interventions" by users of the system, in a dominant private provider model.

It may be unfair to say that quality is unmeasured in healthcare in India. Health care providers project "quality inputs" like technology, physical infrastructure, ambience, and healthcare workforce as quality indicators.

In recent times accreditation bodies like "National accreditation body for Hospitals and healthcare providers" or NABH has made significant progress in bringing this dialogue to centre stage. These efforts are dominantly process-centric and some indicators of outcome also being captured. The momentum is encouraging, with third-party payers valuing accreditation and promoting a higher fee for service for acknowledged quality providers.

It may not be a fair argument to project lack of capabilities, capacity, data capture, and analytics as limiting factors. There are potential opportunities to pursue this goal utilising a wealth of data source that lies in Insurance claims. An analysis will provide insight into the outcome, cost, and length of stay for a diverse set of medical conditions for which third-party payment payers have payment systems. There have been small academic initiatives of such analysis, but we may need to broaden scale and scope.

Similarly, accreditation bodies NABH mandate collection of data on Hospital-acquired infections, safety events which have a negative impact on the health of hospitalised patients. Here again, the collective and systematic analysis is not pursued. As a regulator, the government does not mandate the submission of critical specific patient outcome data to be an integral part of hospital licensing. Given the profound variance in access, type of care, proficiency, skills of the healthcare team, technology, cost and quality across regions, states and cities, such initiatives would provide a view of secondary or tertiary level curative care in Tier I and Tier II cities.

In a way, Indian healthcare has the potential to be a good system but remains far from an ideal one which the country needs. As we transition to become a better health care system regarding effectiveness, efficiency, and equity, it is apt to focus on quality, the right way. Hence it is imperative that patients and their advocates aggressively demand from the other stakeholders in health care that "outcome" matters the most, above all. We all owe it to ourselves.

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The keynote speaker at the Seattle meeting Dr.Clive Callendar from Howard University, Washington, DC, USA has championed organ donation amongst the African American community in the USA. He established the 'Minority Organ Tissue Transplant Education Program' (MOTTEP) and over the last two decades the organisation has been responsible for the increase in the donor registration and currently the UNOS data shows that the rate of donation among blacks is either comparable to white population or better than most ethnic groups. Dr. Callendar in his address stressed the need for public engagement and creating community awareness at the grassroot level (2). This strategy helped improve the rate of donation among the black population and it has risen over the last decade.

MOHAN USA is hoping to make a difference and improve the rate of donation among the Asian Indians in the USA. Dr. Anirban Bose, the president of the group has drawn up a plan to address the issue. Similar efforts are being made in the UK through the MoU signed between MOHAN India and National Health Services Blood and Transplant services of the UK.

#### Ref-

- 1.<https://nhsbtdbe.blob.core.windows.net/umbraco-assets/1849/bame-organ-donation-and-transplantation-data-2017-18.pdf>
- 2.National MOTTEP: educating to prevent the need for transplantation. Minority Organ Tissue Transplant Education Program. Callender CO1, Miles PV, Hall MB. Ethn Dis. 2002 Winter;12(1):S1-S4-7.





## 5th FORT-MOHAN Foundation Training on Transplant Coordination organised under the aegis of NOTTO, Gurugram

MOHAN Foundation in partnership with FORT (Fortis Organ Retrieval & Transplant) under the aegis of NOTTO (National Organ & Tissue Transplant Organization) successfully completed the 'Training on Transplant Coordination' from 3rd to 7th April 2018. It was held at Fortis Memorial Research Institute, Gurugram. This was the fifth consecutive year the training was held in partnership with FORT under the guidance of Dr. Avnish Seth (Director, FORT), and the 19th one-week training in partnership with NOTTO. The training was supported by Tata Trusts.

A total of 41 delegates of varied profiles - transplant coordinators, doctors, nurses, medical social workers, senior managers, medical superintendent and counsellors from 14 states of India (Uttar Pradesh, Gujarat, Karnataka, Maharashtra, Rajasthan, Delhi, Kerala, Haryana, Bihar, Madhya Pradesh, Punjab, Andhra Pradesh, Himachal Pradesh and West Bengal) attended the training.

A panel discussion was held on the last day where the queries of the participants were addressed. The panelists were Dr. Vimal Bhandari (Director NOTTO), Ms. Dhaarna Yadav (ACP, Gurugram), Dr. Anil Agarwal (Chairman, Delhi Organ Transplant Cell), Dr. Sandeep Dewan (Director & HOD, Critical Care Medicine, FMRI), and Dr. Sumana Navin (Course Director, MOHAN Foundation). There were discussions on medico-legal cases, brainstem death certification and time of death, queries related to disconnection of ventilator after the apnoea test and the grey areas where the Transplantation of Human Organs and Tissues Act still needs to give a clear-cut clarification.

Certificates were distributed by Dr. Vimal Bhandari, Director, NOTTO and Ms. Dhaarna Yadav, ACP Gurugram to all the delegates who had successfully completed the 5 days training programme.



Panel Discussion on Current Issues in Organ Donation & Transplantation



Ms. Pallavi Kumar addressing a participant's enquiry



Dr. Sumana Navin conducting a participatory session on ethics of organ donation



Col Sandhya Nair demonstrating the packaging of organs post retrieval



(L-R) Ms. Pallavi Kumar, Ms. Dhaarna Yadav, Dr. Vimal Bhandari, Dr. Sumana Navin and Dr. Avnish Seth (behind) felicitating a participant

## 9th One Month Transplant Coordinators' Training Programme held in Chennai



Mrs. Lalitha Raghuram explaining Swap Donation



Dr. Malini Girish (on the right) along with Dr. Sumana Navin pointing out the parts of the human body





(L-R) Ms. Sujatha Suriyamoorthi and Dr. Sumana Navin presenting a faculty certificate to Mr. Veerapandian who also received a standing ovation by the participants



Mr. Shankarganesh sharing his views during the panel discussion

MOHAN Foundation in collaboration with the Transplant Authority of Tamil Nadu (TRANSTAN) conducted a One Month Transplant Coordinators' Training Programme from 2nd to 29th May 2018 in Chennai. A total of 33 candidates from West Bengal, Andhra Pradesh, Kerala, Karnataka, Puducherry and Tamil Nadu were present. The participants hailed from various professional backgrounds primarily social work, nursing, dialysis technology and administration. There was also a participant, Mr. Pradhap G, who belonged to a donor family - his uncle's organs were donated in Puducherry.

National Organ & Tissue Transplant Organisation (NOTTO), Directorate General of Health Services, Ministry of Health and Family Welfare, Govt. of India, accredited one week of the training. The participants received completion certificates with a unique registration number from NOTTO. The training had eminent speakers from Tamil Nadu, Puducherry and Delhi (via Skype). This was the 9th one-month training programme conducted by MOHAN Foundation and the 20th one-week training in partnership with NOTTO. The training was supported by Tata Trusts.

The final session of the training was a panel discussion by senior transplant coordinators. The panel discussion was moderated by Ms. Sujatha Suriyamoorthi. The coordinators who participated in the panel discussion were Ms. Sendhamarai Selvi, Mr. Sagayam Francis, Mr. Shankarganesh K, Mr. Shivakumar, Mr. Senthil Kumar, Mr. Sathish L, Mr. Dhanaraj, Mr. Johnson and Mr. Prakash. How to overcome stress while working, as transplant coordinators, will the hospital support transplant coordinators when challenging situations arise, what are the career growth opportunities available for coordinators, how important is it to work in a team and build a network, should the families of deceased donors receive compensation were some of the questions that were raised and discussed.

At the valedictory function, the participants received their completion certificates from Dr. K. Jayanth Murali, IPS, Director, Directorate of Vigilance and Anti corruption, Dr. P.Balaji, Member Secretary, TRANSTAN, Dr. N. Gopalakrishnan, Prof. & Head, Dept. of Nephrology, Madras Medical College, Dr. U. Amaleshwari, Director-School of Management, D. G. Vaishnav College, and Dr. Sunil Shroff, Managing Trustee, MOHAN Foundation. Dr. Vimal Bhandari, Director, NOTTO was also present via Skype.



Ms. Anusuya. A receiving a completion certificate from Dr. K. Jayanth Murali, IPS, Director, Directorate of Vigilance and Anti corruption at the valedictory function. All seen Dr. N. Gopalakrishnan, Prof. & Head, Dept. of Nephrology, Madras Medical College



Group photo during the valedictory function



## Advanced Transplant Coordinators' Workshop - 'Let us Refocus' held in Chennai



Dr. Darius Mirza, Professor of HPB and Transplant Surgery, University Hospital Birmingham and Birmingham Children's Hospital explaining on the benefits of Donation after Cardiac Death



Ms. Jayanthi Sampathkumar sharing her experience about her journey as a marathoner



Mrs. Thilaka Ravi speaking on content writing for the web



Activity on advocacy



Activity on roles and responsibilities during a donation



Speakers and delegates at the conference

The Advanced Transplant Coordinators' Workshop was held on the 23rd and 24th of March 2018 in Chennai. The theme of the workshop 'Let us Refocus' helped the participants of MOHAN Foundation from Delhi, Mumbai, Nagpur, Hyderabad, Madurai, Salem, Coimbatore and Chennai focus on the cause and share their views.

Eminent faculty were also invited to speak at the workshop. Dr. Darius Mirza, Professor of HPB and Transplant Surgery, University Hospital Birmingham and Birmingham Children's Hospital was the guest speaker. He explained the benefits of Donation after Cardiac Death, he also put forth the question to the audience 'DCD in India – Is India ready?' Ms. Jayanthi Sampathkumar, IT Manager, Microsoft spoke about her journey as a marathoner, how the idea of running in a saree was birthed and what pushed her to make the cut for the Guinness Book of World Records. She focused on the importance of mental strength in addition to physical fitness.

Mr. Gowtham, Founder & Market Strategy Consultant, Brand That Social touched upon the various ways that social media works and how far the message of organ donation can be spread. Ms. Thilaka Ravi, Reporter, Writer, Quality Control Overseer – Medindia, Professor – Institute of Distance Education (IDE), University of Madras pointed out the common errors one makes in content writing for the web and Ms. Amala, Medindia illustrated how infographics can deliver information in a succinct manner.

Dr. Sunil Shroff enlightened the audience about the Memorandum of Understanding (MoU) with the NHS Blood and Transplant, UK and the various opportunities provided for coordinators. Dr. Satya Vrat Sharma, MBE, Chair, Promoting Organ Donation (POD), UK addressed the gathering via Skype. He mentioned that after signing the MoU, a lot of activities have been carried out. He stressed working more intensively with the BAME community and sought MOHAN Foundation's help in getting celebrities like cricketers and actors to support organ donation with the BAME community in the UK.

Dr. Anirban Bose, Nephrologist, Strong Memorial Hospital, United States via Skype spoke about the role of MOHAN USA and its accomplishments thus far, he went on to speak about the upcoming fundraiser in Seattle, USA. Dr. Sridhar Nagaiyan, Senior ICU Consultant, Kauvery Hospital helped the participants understand the usefulness of apps & simulations in learning.



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