



MOHAN
FOUNDATION

You are the clay
You are the potter

A Tribute to Transplant Coordinators

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FOREWORD

"The best and most beautiful things in the world cannot be seen or even touched. They must be felt with the heart."

~ HELEN KELLER

WHEN THE WORLD witnesses the miracle of organ transplantation what they often fail to see are the invisible efforts of Transplant Coordinators which help to transform and save lives. What they don't get to witness are the arduous and long hours that the Coordinators spend with the families in having the difficult conversation about organ donation, at a time of extreme grief. What they are often oblivious to is the passion that gives these Coordinators the courage and conviction to pursue, where many would hesitate.

Death is not the greatest loss in life. The ultimate loss is when we fail to give families the choice to save multiple lives and let their loved ones live through others. Transplant Coordinators have helped many families make this difficult choice by supporting them in their darkest hours.

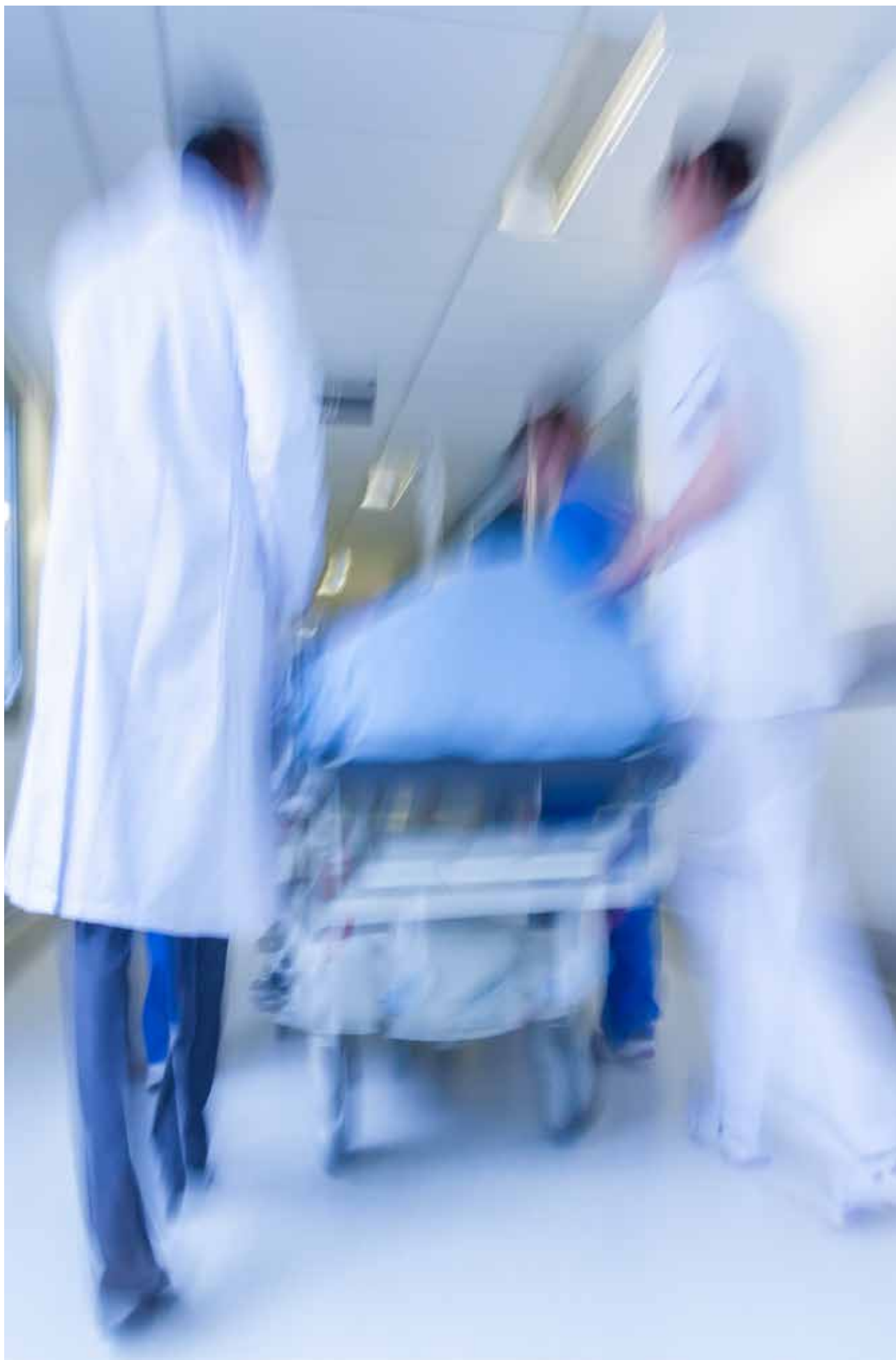
Every family is unique, every story is different and every incident challenging. Each experience hones the Coordinator into a true champion of the cause, the cause that saves countless lives through the act of organ donation and transplantation.

This compendium is a tribute to the work of the Transplant Coordinators, to their countless hours of dedication and to their boundless enthusiasm to work towards saving lives of people unknown to them. The gift of life through organ donation and transplantation is the true miracle of modern medicine and I sincerely feel that the Transplant Coordinators are the custodians of that gift.

Dr Sunil Shroff
Founder & Managing Trustee, MOHAN Foundation

"As you move outside of your comfort zone, what was once the unknown and frightening becomes your new normal."

~ ROBIN S SHARMA



INTRODUCTION

AT THE HEART of making deceased organ donation a reality are a few passionate individuals known as the Transplant Coordinators. They are critical in guiding grieving families, at what could perhaps be the most challenging time in their life, to arrive at the very difficult decision of donating the organs of their deceased loved ones. Transplant Coordinators perform what is often a thankless but an extremely gratifying task. For them, each story is different, each family unique and each conversation novel. Therefore, they need to be as malleable as clay but at the same time be creative as a potter to shape the desired outcome.

MOHAN Foundation started the one week long Transplant Coordinators Training Programme in 2009 and since then has trained over 2100 Transplant Coordinators. It also conducts a One-month training for Graduates who are freshers in this field and a One-year Post Graduate Diploma in Transplant Coordination and Grief Counselling (online course) for working professionals who wish to add weightage to their qualification.

The Foundation has been conducting the National Annual Transplant Coordinators' Conference every year in order to provide a unique and much needed platform for synergistic learning through sharing of experiences and best practices. It also provides an opportunity for them to network and engage and build a sense of community.

MOHAN Foundation was also instrumental in the formation of NATCO (Network and Alliance of Transplant Coordinators), a registered non-profit, membership-based organisation established to give a unified voice to all the Transplant Coordinators in the country.

In order to recognize and honour the work of the Transplant Coordinators, MOHAN Foundation instituted the 'Swamy Narayan Best Transplant Coordinators' Award' which has over time become the most coveted award for Transplant Coordinators and the gold standard for best performing Transplant Coordinators.

Organ donation in our country faces many challenges and hurdles as there is a lack of a streamlined system in place. Despite the severe odds, the Transplant Coordinators continue on their difficult path with determined passion. The stories of Transplant Coordinators and the challenges they face while counseling and managing an organ donation or transplant often go unacknowledged. MOHAN Foundation recognizes the strong need to celebrate the efforts of these Transplant Coordinators and showcase their experiences and struggles as they engage with families of potential organ donors.

In another first, MOHAN Foundation is pleased to present this compendium- You are the Clay, You are the Potter- saluting the unsung heroes of deceased organ donation and transplantation in India. •



YOU ARE THE CLAY, YOU ARE THE POTTER

This write-up is dedicated to all the grief counselors that work relentlessly round the clock with minimal support in a trying environment, so that those patients that are waiting with bated breath are provided with the much needed organs for transplantation.

GRIEF, THE FIVE LETTER WORD is such a devastating one that it could forever change the way a person views life. Loss of a dear one devastates the entire family in more than one way. Grief shakes your personality, your belief and the outlook towards life. Family members suffering grief take anywhere between few months, years and sometime a life time to come to terms with their loss.

Counseling under normal circumstances can be for different reasons and the outcome could lead to very positive and happy endings. On the other hand, grief counseling requires skill, confidence, knowledge of the situation and a great understanding of sensibilities.

Professional grief counselors adopt several time tested techniques and

offer support to individuals and families. They spend enormous amount of time and meet periodically and offer them comfort and solace as per the needs of the individual or family. They help them in developing skills using different methods and engaging in different activities. While some advocate their clients to adopt some art therapy, some are advised to engage in some activity that their loved one would have liked. This process is long, often slow paced and time consuming,

Counseling bereaved families for organ donation is completely different, in that it offers very little time to truly provide comfort to the families. The Transplantation of Human Organs Act, 1994 specifies that declaration of brain death has to be made twice, at an interval of six hours. At a time when the treating clinician breaks the bad news about "death", family is still grappling with a difficult situation. In India, where the concept of "brain death" is relatively unknown to lay public, families are left to their imagination about the condition of their patient. With different settings in different type of hospitals, the clinician may have very little or no time to explain or emphasize the concept of brain death repeatedly. It is at these trying moments that a grief counselor uses his/her skills to unravel the clinical jargon into an easily understandable process, so that the family is able to come to terms with their loss. As proposed by Prof. Elisabeth Kubler Ross on the five stages of grief, the families could go through denial, anger, bargaining, depression and acceptance. Although this was proposed in 1960s these five stages are very relevant in present days and to organ donation too.

Denial: Families, however much they have been primed about imminent death, go through significant denial when the doctor breaks or pronounces death of their loved one. The grief counselor has to patiently adopt a "wait and watch" technique and be "available" for the family for any questions or doubts that they may have. Gradually, they have to take the family into confidence and explain to them as to what their loved one has gone through. In order for this information to sink into their conscience, it may be wise for the grief counselor to make them repeat what they have understood. That way, the family members would have internalized the reality.

Anger: Anger can manifest in many different ways. When their loved one was brought into the Emergency Room, if there was a delay by a doctor attending on them, family could be angry on the doctor. Some family members may be angry on doctors for lack of communication. Lack of trust on doctors is growing significantly in India, to the extent that the families not only get angry, but are also violent. The grief counselor has to use their best skills to try and sort out this issue as much as possible. This situation cannot be suppressed or wished away. After all, everyone has a right to be angry. Sometimes, the anger could be on God or themselves. The grief counselor has to appear calm and the body language has to demonstrate that they are available to provide emotional support.



Lalitha Raghuram is a compassionate, enthusiastic and a high-integrity individual and as the Country Director of MOHAN Foundation, she is committed towards achieving organizational objectives through optimal leverage of human & technological resources. She has a rich, broad-based expertise in health care management arising out of 27 years of experience with leading eye care and not-for-profit organizations around the world. She was an Administrator of L.V. Prasad Eye Institute for seven years (1986-93), following which she became the Executive Director of Eye Bank Association of India, where she served for 9 years (1993-2002). Having been trained internationally in USA, Prague and UK, she started MOHAN Foundation in Hyderabad in 2002. In the year 2004 Lalitha's passionate commitment to her profession transcended a deep personal tragedy. In a tragic incident, her young 19-year-old son had a fatal road accident and was declared brain dead. Walking the talk, Lalitha and her husband took the heart-breaking but inspiring decision to donate their son's organs. For this brave and noble action, they were presented the CNN IBN Real Heroes Award. They received a trophy and a cash award of INR 5 Lakhs, which they have donated to MOHAN Foundation to further the cause of organ donation. Most recently, Lalitha has been inducted as an "Ashoka Fellow." Ashoka Fellows are social entrepreneurs who have made a difference in society through their innovative work. She has also received the "Rotary Vocational Excellence Award" and "Woman in Transplantation Hero Award" amongst several other awards.

Bargaining: The family members may bargain with God and ask for forgiveness for their wrong deeds. They may bargain to pardon their loved one, and to transmit the punishment to themselves.

The families may also bargain with doctors, advising them to get a “better specialist” and express willingness to spend any amount of money. Some may bargain to seek a second opinion from a doctor from a different hospital.

Depression: This is perhaps the most difficult phase that family members experience. When it dawns on them that the imminent has indeed occurred, they experience guilt, fear and hopelessness. The grief counselor has to demonstrate significant patience at this time and make the families understand that it is absolutely normal for anyone to go through this and that they do not require to be shy to express their feelings. The grief counselor has to demonstrate that they truly care for them and encourage them to express their feelings. It is impossible to take away their pain or fix their problem.

Acceptance: Enormous support, sufficient time and an unconditional understanding of the family’s situation by a trained grief counselor can help the families move to “acceptance” stage swiftly.

Deceased organ donation is slowly gaining acceptance in India. While the South, West and some parts of North India has taken roots, other States are slowly initiating the program. While brain death identification remains a significant challenge in the country, availability of trained grief counselors is yet another impediment that needs attention.

MOHAN Foundation (Multi Organ Harvesting Aid Network) is a non-profit organization established in 1997 in Chennai, with a mission to educate the cross section of the population about deceased organ donation and to create a sustainable environment to augment organ donations. As part of its capacity building initiatives, MOHAN Foundation has trained over 2100 Transplant Coordinators that take up the onerous task of (a) grief counseling and (b) coordination with various agencies for a smooth organ retrieval process.

Typically, a Transplant Coordinator has very little time for grief counseling given that there is a short window between two declarations of brain death. They experience enormous pressure from doctors and hospital management to get a positive response for organ donation from the bereaved family. However, it is important for all health care professionals to understand that grieving families take time to accept death. In addition, organ donation is a new concept that they may not have heard at all. When the families are grieving, the grief counselor is vested with the responsibility of asking for organs which they may not have considered at all, or offer the organs to a complete stranger about whom they know nothing. Hence, the transplant team members have to demonstrate patience and show solidarity to the Transplant Coordinator and respect the families taking time for decision making.

There may be a need for several rounds of grief counseling and to differ-



ent members of family and that requires patience. As time is of essence, the grief counselor has to professionally stress on the need for making a positive decision at the earliest, lest the organs become unviable.

During the last decade, India has witnessed organ donors that are mostly victims of road traffic that are in their productive years of life. In such cases, autopsy becomes imminent. The Transplant Coordinator plays a pivotal role in coordinating with different departments within the hospital and also with external agencies like the police and forensic departments. Cremation typically takes place between sunrise and sunset. Hence, families request for body of their loved one to be handed to them before sunrise. While the families engage themselves with the funeral arrangements, the Transplant Coordinator is left to handle the more difficult aspects culminating to organ donation, not to forget that the family’s needs must be “high priority”.

Two decades of experience of MOHAN Foundation’s Transplant Coordinators reveal that providing some comforts to the family, like a private room, food and water, is considered professional. At a time when families are tired making trips between outpatient department, ICU, pharmacy, canteen and billing department, these small comforts provide the much needed solace for their tired body.

A negative response: Should the family “decline” to donate organs, it is advisable for the grief counselor to continue providing support to the families. This will help demonstrate that they “care” irrespective of the outcome of their counseling.

It is a good idea for the hospitals to examine why there has been a negative response from the family, so that they may refine their approaches. However, it may be harmful to assess the grief counselors' performance based on the number of "Yes" they have obtained for donation, as there may be several other contributory factors that require attention.

Deceased organ donations in western countries have the concept of "Organ Procuring Organizations" (OPOs), where the entire process of deceased organ donation is maintained and controlled by them. However, India does not have this model in place. However, there are predominantly FOUR models that are prevalent here. Let us examine these models.

An in-house Transplant Coordinator: In India, all licensed transplant centres have trained Transplant Coordinators. However, most of them are engaged in the arduous documentation required for performing "live donor transplantation". However, the hospital management expect them to take care of recipient and donor coordination. In a high volume transplant centre, this could be quite a challenge, and the grief counselor may not be able to perform effectively, as their time is divided between the families that are suffering loss of their loved one and a potential organ recipient. Their focus on grief counseling may be minimal or completely unavailable. This will obviously result in a diminished successful consent. When the Transplant Coordinator is unable to obtain consent from the family, the management and transplant team views the Transplant Coordinator as being ineffective or a failure.

Counseling by an external grief counselor with the support of an in-house Transplant Coordinator: This model is gradually gaining popularity. The in-house Transplant Coordinator is put in the "scene of action" by the clinician declaring brain death. Then the Transplant Coordinator takes over and gets all the necessary information from the medical records, nurses and from family conversation. Then, an external Transplant Coordinator (from organizations such as MOHAN Foundation) is notified, who develops a rapport with the family and broaches organ donation. This eases the in-house Transplant Coordinator of the onerous task of doing multiple counseling, spending enormous amount of time with the family and waiting to hear on their thoughts on organ donation.

The external Transplant Coordinator updates the management and transplant teams from time to time on the status of family's response. It is observed that the family is at ease discussing with an external agency that is not involve in the care of the patient. In addition, the families may not view this professional with any suspicion as compared to an in-house professional.

Counseling by an external Transplant Coordinator in a government hospital: In India, government hospitals experience a high volume of patients and do not have an exclusive Transplant Coordinator. In this situation, the State agencies such as TRANSTAN in Tamil Nadu or Jeevandan

in Telangana have entered into a Memorandum of Understanding with MOHAN Foundation to have their trained Transplant Coordinators to be placed in government hospitals. These Transplant Coordinators perform the unenviable task of developing a rapport with the Heads of Department, other doctors in the department, post graduates and ICU nurses. They conduct several "Hospital Education" programs and engage actively with all the concerned team members. They so conduct themselves that they become part of the team. In a situation where there is inadequate infrastructure, fewer doctors and high volume patients, the Transplant Coordinator makes an effort on grief counseling every time a brain death is declared. It may be noted that the patients in such hospitals are from lower socio economic status, partially or not educated at all. While the western world propagates a private setting for grief counseling, the Transplant Coordinator here counsels in the corridor of the hospital. They have to make do with what is available at that time. They have to first explain brain death in a way that they are able to understand and gradually solicit organs. It is beyond anyone's imagination how these families say "YES" to organ donation. The generosity that they demonstrate during their grief may be no less than war heroes. Once they obtain consent from the families, they work very hard until the organs are retrieved and body handed to the family.

The Transplant Coordinators put behind their personal needs like food, water or rest and their utmost. The "Icing on the cake" in this model is that the patients (on waiting list) in government hospitals get the first choice at these organs, be it a heart, liver, lungs or kidneys. A Chennai based government hospital performed a successful "Hand Transplantation" recently.

Counseling by an external Grief Counselor in a Corporate Hospital: The fourth model is where a corporate hospital has a Memorandum of Understanding with MOHAN Foundation, wherein a grief counselor works full time within the hospital for deceased organ donation program. The Transplant Coordinator takes care of public education within and outside the hospital, "Hospital professional education" and makes ICU rounds with doctors. At this time, they develop a rapport with all the concerned team members and also with the families of patients in ICU. They are stationed outside the ICU and quite often support the families with their visitors, finding housing for them (wherever required) and providing locally relevant information. At a time when brain death is declared by the doctor, these Transplant Coordinators would have known the patient's family already, which provides them with the comfort of asking for organs of their loved one. Here, the first and most important step of "rapport building" has been taken care of effectively.

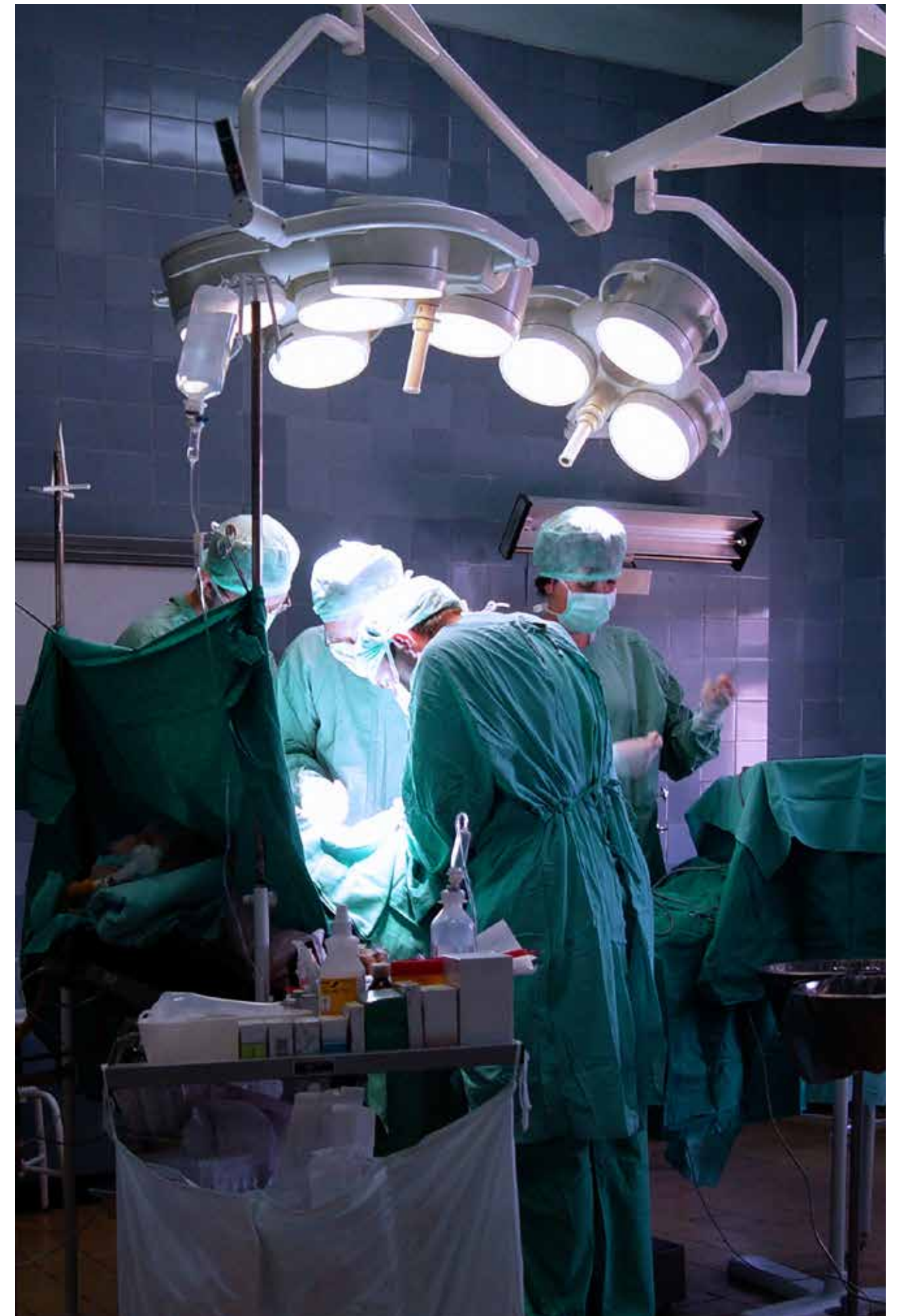
MOHAN Foundation's Transplant Coordinators continue to work in all the four models mentioned above and have demonstrated good success.

At a time when organ donation program is receiving significant attention in at least two-thirds States of India, it would be interesting to see how this program evolves in rest of the country.

The deceased donation program requires Commitment, Consistency, Care and good Communication. Many youngsters have to choose this as their career option, so that this cadre becomes popular and most “sought after” by the health care professionals. •

Why the title, “You are the Clay, you are the Potter”?

Deceased organ donation has been initiated by passionate individuals that established non-governmental organizations several years ago, when structured stipulations or guidelines from government was unavailable. During the last decade, several state governments have given this program the much needed impetus. Central government has been active in this program for the past four years. As a result, this program has taken its own shape as the need may arise. Transplant Coordinators have adapted to this system with an inherent passion and commitment much like a creeper would cling to a strong tree. In that sense, the Grief Counselor/Transplant Coordinator is a clay and shapes his/her approach based on the hospital environment. They face the triumphs and challenges, make mistakes, falter and gradually experience success.



STORIES FROM THE HEART



These are heart-warming stories written by *Transplant Coordinators* across the country about a particular donation they coordinated or a family that impacted them.

WHEN DONOR FAMILIES BECOME DONATION ADVOCATES



Anindita Sabath is a hard-working social worker, who is sensitive & empathetic to the everyday problems of the people around her. She works as a Transplant Coordinator in MOHAN Foundation, Delhi - NCR & has been in this field since the last one & half years. She hails from Odisha & likes experimenting with her culinary skills.

ON JULY 18, 2018 at 1500 hours, I got a call from the Medical Social Worker of the hospital (where I am deputed as a MOHAN Foundation Transplant Coordinator) that there was a potential brain dead donor in the critical care unit and the family wanted to discuss the option of organ donation.

Ms.Mehta (name changed), a 72 year old spiritual woman stayed alone in her home in Ghaziabad. Her husband had expired 3 years back. She had two married sons settled in Delhi and Bangalore respectively. She had no health problems except hypertension. On July 15, 2018 she had complained of sudden headache followed by 2-3 episodes of vomiting. She was then rushed to the hospital where she was diagnosed with Sub Arachnoid Haemorrhage.

In the previous counselling sessions, the children were clearly informed about the poor prognosis of their mother and also that donating her organs was another option that they could look into.

When I arrived in the counselling room, the elder son, the daughter in law and the younger son were present. I introduced myself to the family and started the conversation by finding out details of their family and condition of their mother as shared by the treating doctor. "Now we are sure that our mother is not going to come back to us so we would like to donate her organs so that some people can get a chance to live. I am sure my mother's soul would be happy with this decision of ours and she will rest in peace now", said her elder son. It was very gratifying for me to hear this from the family, especially since most families find this a very difficult decision to make. I recorded their consent on the consent form and informed the critical care team as well as the transplant teams.

In due course of time, the retrieval took place and next morning the body was finally handed over to the family with utmost respect. Her liver and one kidney went to the recipients of the host hospital. Other kidney was shared with another private hospital.

While leaving the hospital, the daughter in law held my hand and said, "Thank you for giving Mummy ji the opportunity to continue to live on in some people even after leaving this world. We would appreciate your



presence in the prayer ceremony that will be held at our Ghaziabad residence. We will take care of your travel. We want you to come and address our guests about organ donation and the work you do.” I was extremely surprised to hear this. The emotional strength the family exhibited was exemplary. I immediately accepted the invitation.

I attended the prayer ceremony after four days. To my surprise, the religious guru who was offering the prayers was asked to speak about organ donation and also shared what the Hindu scriptures said regarding ‘daan’(giving). The son, while addressing the gathering, shared the dismal organ donation statistics in the country and how people are dying on waiting lists. He urged them to think about this important, life-saving cause. After the ceremony was over, many guests came up and collected fliers on organ donation and also took donor cards to pledge to donate their organs.

On my way back, thinking over the course of events I was overwhelmed thinking how a family, despite their personal grief, took this brave decision to donate organs and then go a step further in using this opportunity to promote awareness on the cause of organ donation.

I am indeed grateful to donor families who take such valiant decisions and by doing so inspire others. •

THE FIRST LUNG DONATION IN MADHYA PRADESH

DECEMBER 2018 My day starts with the same routine of ICU rounds. The familiar sight and sounds of the ICU greet me as I enter -the beeps and sounds of various machines and monitors, tubes and lines attached to patients – an on-going struggle to survive, the endless battle for life.

When I reached bed number 212, I saw the patient Babita (name changed) lying with ET tube in situ, the pulse oximeter beeping constantly and the attending nurse trying to feed her via Ryles tube. She is only 36 year old, a loving sister to two brothers. They lost their father to end stage kidney disease and knew the importance of organ donation to save the lives of people living with end stage organ failure.

A few days ago, Babita was at home when her brother told her that he had pain in his chest. He seemed to be in discomfort and while she was attending to him, she suddenly fell down and became unconscious. In a strange twist of events, it was the brother who had to rush her to the hospital where she was immediately intubated and had to be put on life support. The CT scans showed a massive basal ganglion bleed. Soon her pupils became unresponsive.

The treating team tried their level best but nothing helped. She was declared brain dead.

Even before I could initiate a conversation on organ donation, her brother quietly said, “Babita wanted all her organs to be donated as our father died due to unavailability of an organ. He could not undergo a kidney transplant in time and as a family, we understand the plight of those living desperate lives waiting for an organ.” The brother also shared that every time Babita read an article or story on organ donation in the city, it would touch her. She once remarked, “Yeh hoti hai zindagi! Jeete jee to bohot kuch kar sakte hain par agar marne ke baad bhee kisse ko jeevan diya to yeh hee sahi mayane mai zindagi jee.”

The brother told me that their mother was 86 years old and was a cardiac patient. He said that the family would discuss the same with her and will convince her for organ donation. He later reverted with the decision of the family to go ahead for organ donation. While he was a pillar of strength during this entire process, he finally broke down when Babita was being taken to the operating room for retrieval.

Her heart, liver, kidneys and corneas were transplanted to others waiting for life saving organs but for the first time in Indore and the whole of Madhya Pradesh, a lung retrieval took place, making Babita the first lung



Dr.Amit Joshi works as a OSD (Officer on Special Duty) Medical Administration and Transplant Coordinator at Bombay Hospital, Indore (MP) Amit has coordinated more than 35 deceased organ donations in Indore and was involved in the first Lung retrieval at Bombay Hospital which was also the first Lung retrieval of MP. He has conducted more than 250 awareness activities on organ donation throughout Madhya Pradesh. He is an active volunteer of Indore Society for Organ Donation, Indore His wife Poonam is his inspiration who not only is a big supporter of his work but also helps him with new ideas.

donor in the state.

The courage showed by Babita's brother during such a tragic and untimely death is unprecedented. There are no words to thank the family for their contribution to humanity. The spirit of Babita lives on...•

THE FIRST DONATION EXPERIENCE OF PUNE



Arati Gokhale is working as a Central Coordinator of ZTCC (Zonal Transplant Coordination Committee), Pune. She has been working in this field since 1994 and her journey started with eye banking in Ruby Hall Clinic.

Her role as the Central Coordinator involves maintaining waiting list of recipients, allocation of organs, creating public awareness and organising workshops and on-going training for health professionals and Transplant Coordinators in her zone.

Her husband is an Engineer and she has two grown up daughters. She has tremendous support from her family for the work she does. She loves to dance on Bollywood numbers and meeting new people.

ON THE AUSPICIOUS DAY of Gudipadva on April 10, 1997, Ruby Hall Clinic was felicitating living related kidney donors to celebrate the completion of 50 kidney transplants.

On the same day, a very unusual but encouraging news was flashing on all major news channels - Mumbai had facilitated its first successful deceased organ donation. This was Maharashtra's first voluntary organ donation after the implementation of HOTA (Human Organ Transplant Act) in 1994. Both the kidneys were harvested and transplanted to others on the waiting list.

This news greatly inspired the doctors at Ruby Hall and as fate would have it, that very evening Dr. Prachee Sathe, in charge of the ICU, communicated that there was a patient who was brain-dead as defined in HOTA 1994.

The entire hospital was closely observing the situation. There was a lot of anxiety and trepidation. The patient was a Road Traffic Accident (RTA) victim. He was married with two children. It was a tragic case and we all were concerned for the family.

The next morning, Dr. Sathe spoke to the family of the patient. Neurological examinations had been done along with the first apnoea test and she explained the condition to the relatives. After the second confirmatory test she called the brother of the patient to the ICU and explained that his brain had stopped functioning and that he was no more and had died.

This was the first time that the doctors and I were considering approaching a family for organ donation, we were unsure. When the relatives finally asked for the body for final rites, Dr Sathe mustered the courage to give them the option for organ donation. The entire situation turned around and the relatives began considering the option but could not come to any conclusion. They seemed confused and restless.

In the midst of all this, an elderly man approached the hospital looking for the hospital head. This person was the maternal uncle of the patient who was brain-dead. He had, some time ago, donated a kidney to his son and therefore was aware of the need for organs. The uncle accompanied by me and a few other relatives met the hospital head in his OPD. This



gentleman was able to convince the relatives who eventually gave consent for donating both the kidneys of the brain dead patient.

We had mixed feelings - while we were sad at the loss of the family, at the same time we were excited to be a part of the first ever deceased organ donation and renal transplant in Pune. The excitement was palpable everywhere. After getting an official consent, donor was shifted to OT the next day.

There was a dramatic turn of events. A big mob of people suddenly arrived at the hospital out of nowhere. They were agitated and suspected foul play. Many felt that other organs were also being retrieved without family's permission. The hospital had to call the police to control the situation. At the same time Dr. Sathe and me spoke with the close relatives and explained to them that everything was being done legally and in a transparent manner. Thankfully everything came under control and we heaved a sigh of relief.

I, along with my colleague, had spent more than 48 hours in the hospital coordinating this case. We were exhausted and spent but elated that we, along with the hospital, had made history. No doubt it had been challenging, like every case is, but this special family made us see the way forward. We will always cherish their contribution to the cause, especially in Pune.

After a few months, the team at Ruby Hall was felicitated by Hon. Health Minister in Mumbai for the "First donation" in entire Maharashtra outside Mumbai. It was a great Honor to accept this award for this cause. •

EVERY DARK CLOUD HAS A SILVER LINING



Dr. Bhanu Chandra is the Operations Manager at MOHAN Foundation, Hyderabad and presently posted at Osmania General Hospital, Hyderabad as Senior Transplant Coordinator through the Jeevandan initiative of the State of Telangana.

With a Bachelor in Physiotherapy and a Masters in Hospital Management, Bhanu has over 10 years of experience in the field of organ donation. He has counseled and coordinated more than 350 organ donation cases. He received the best Transplant Coordinator award for the year 2015 from MOHAN Foundation.

Bhanu lives in Hyderabad with his parents, wife and two kids

AS A TRAINED TRANSPLANT Coordinator working for MOHAN Foundation, an NGO that promotes the noble act of organ donation, I feel all donor families that we work with impact us in some way or the other. However, some cases leave a more profound impression. The case I am sharing here tested all my knowledge, skills and acumen as a Transplant Coordinator.

I was informed about a potential organ donor in the ICU of a government hospital. On reaching the hospital I took the details of the patient from the treating team. Ms. Suman (name changed) a 28-year-old married female, was admitted to the hospital with hypoxic brain injury caused by hanging and she was declared brain dead by the doctors.

After obtaining all the medical information, I met the patient's family - her mother, father, sisters, brothers and other relatives - in the counselling room. During the counselling, when explained about her condition, they were not ready to believe that the patient was dead. They wished to speak to the higher authorities.

I decided to wait and give some time to the family to come to terms with the news of her death. After some time, I again approached the family to initiate a conversation on organ donation. I was unable to bring up the subject as the family members were now accusing the in-laws of the patient for having created circumstances that led the patient to take her life by hanging. I could only give them my support through all this by listening patiently. I felt that by this time I had established a certain degree of trust and relationship with the family.

After some more time had elapsed, I met the family again and gave them the option of organ donation. This time they seemed more amenable to the option of organ donation. Although this was a positive breakthrough to get a unanimous consent from the patient's family, however husband's consent was legally essential if the case had to progress further.

I then contacted the husband who told me that he would come to the hospital with his relatives in the evening. I spoke to the husband and his family and explained the condition of his wife. I also shared with him that his wife's family had agreed for organ donation. After listening to me the husband also gave consent for organ donation.

The paper work formalities were completed by 8.00 pm. I informed the recipient hospitals of the allocation of the organs. Kidneys and liver were allocated to the local hospitals and heart and lungs were shared with other state hospitals.

Being a medico-legal case, police and the forensic authorities were in-

formed and details of the case were shared with them. The local and state recipient hospitals started to get ready for a smooth retrieval process.

In the middle of the night, I received a call from the Circle Inspector informing me that the family had not booked a FIR (First Information Report). I informed the patient's family about it and told them to do the needful. The father of the patient along with other relatives went to the police station to book FIR. The Circle Inspector refused to give the Panchanama as the couple had been only married for 4 years and the Panchanama had to be given by the Mandal Revenue Officer (MRO). At the same time, I received a call from the ICU doctor informing me about the unstable haemodynamics of the patient and if the retrieval process did not happen in time then the patient would crash.

After some time, Circle Inspector (CI) called me again and said that the MRO was not ready to come as there was a suspicion of murder under section 304A due to dowry harassment. I then called a senior IPS officer, a big supporter of the cause, requesting him for his help in the case. He then spoke to the MRO and requested him to cooperate and do the needful by giving the Panchanama. MRO promised to help but later he stopped taking my phone calls.

Finally having exhausted all the options, I requested the treating doctor to maintain the donor till the legal issues were sorted out. Though he was not very confident on the patient's condition, he promised to do his best to keep the donor stable till the morning. I also informed the police, forensic doctor and recipient hospitals about the delay in the retrieval process.

After making several futile attempts to reach the MRO during the night, he finally took my call at 6:15 am and assured me that he will reach the hospital within an hour. I alerted the police and forensic authorities. All the teams reached the hospital except for the MRO, who was again unavailable on phone. The other teams were beginning to get frustrated with the delay. I was having a hard time trying to pacify them. Meanwhile the Assistant Commissioner of Police (ACP) also arrived and took the statement from the family members of the donor. The MRO finally arrived at 08.30 am and the legal formalities began.

At 10.30 am, the donor was wheeled into the OT for retrieval of the organs.

Anyone would think that my painful ordeal would be over as the organs had been retrieved successfully but that was not the case. At 3.00 pm the body was ready to be handed over to the family. However, there was no one to receive the body as the husband and his family members were arrested by the police and the donor's family refused to accept the body.

Discussions with the police, hospital authorities and both the families continued for the whole day regarding the release of the husband from the jail so that the body could be handed over to him. But, nothing materialised.

At 6.00 pm I requested the hospital authorities to keep the body in the mortuary. In the absence of the family members, I filled out the requisite paperwork required to keep the body in the mortuary. After a gruelling 36 hours, which had depleted me physically, mentally and emotionally, I

reached home at midnight.

Subsequently for the next 2 days, the hospital authorities kept calling me to find out as to who would receive the body and when. Finally, the husband was released on bail after two days who then received the body from the mortuary.

Every case is unique and teaches us many new things. We remain students for life.

THE YOUNG BRAVEHEART OF RAJASTHAN

“BHAVNA BAI SA, why didn’t you insist on the donation of the heart ? Today, I would have been able to hear his heartbeat also!” These words, spoken by the father of Mohit (name changed) to Bhavna Jagwani (Convener, MFJCF), resonates in the hearts of the MFJCF (MOHAN Foundation Jaipur Citizen Forum) team till today.

Mohit was a 7 year old student of class III, studying at Rajkiya Prathamik Vidhyalaya School located in Tilwar at Alwar. He was the eldest among four siblings. An intelligent boy, he was always helpful towards others. He would go out of his way to help his classmates. Being a punctual, disciplined and regular student, he was the favourite of the principal and his teachers.

After school he would rush home to help his father in the fields and other farm related activities. He was very close to his mother and was very fond of listening to stories. Sohan Papdi was his favourite sweet. His mother fondly recollects that he was an easy going and affectionate child who was fond of playing with water.

On the last day of January, 2015, Mohit came back from school as usual and was helping his father in the field. On that day his father was chopping fodder in the machine for the cattle. The machine was a basic cutter that ran on an electric motor. It would get heated while in use, so water had to be poured continuously on the wheel to prevent it from overheating and also to prevent the fodder from flying at the wheel. Mohit was pouring water on the wheel as his father fed the long stems of fodder grass into the chopping blades. An unfortunate turn of events led to his jacket sleeve getting entangled in the wheel of the fodder cutting machine and before his panicked father could reach the motor to switch it off, he had gone around the wheel four times, hitting his head on the ground.



Taking into account the severity of his injury his distraught family rushed him to Mahatama Gandhi hospital in Jaipur where the doctors fought for four days to save his life. But fate decreed other wise and he was declared brain dead.

Around that time the Jaipur Citizen Forum (JCF) under the leadership of Ms Bhavna Jagwani had partnered with MOHAN Foundation to initiate the deceased organ donation programme in the state of Rajasthan. The team counselled the family to donate Mohit’s organs. The family battling with their grief walked the path of ultimate humanity as they agreed to donate Mohit’s organs to save other lives. His kidneys and liver were transplanted on February 5, 2015 to others requiring lifesaving transplants.

The father had only one request at that time that he did not wish to donate Mohit’s heart as he wanted to take Mohit back with his heart to the village, Tilwar.

After the cremation however, Mohit’s father called up and said, “We have made a mistake”. Bhavna ji remembers how her heart sank as she thought they regretted their decision of donation. Then the father said, “ “ Bhavna bai sa , why didn’t you insist on the donation of the heart as well? Today I would have been able to hear his heartbeat too.”

Today, a father is able to see his daughter married off because a family decided to let compassion overcome their grief. A mother is able to live and plan because Mohit’s family decided to be the torch bearers for organ donation in Rajasthan. At that time, it was also a very courageous decision as organ donations had not begun to happen in Rajasthan and yet this family chose to do this from the deep well of kindness in their hearts, even though they would have to answer many questions from their extended family and others from the village.

Today we, the MOHAN Foundation Jaipur Citizen Forum (MFJCF) team lives by the motto, “In thoughts, words and deeds, we will keep the cause above ourselves.” •

The groundwork for MOHAN Foundation Jaipur Citizen Forum (MFJCF) was laid 15 years ago when Ms Bhavna Jagwani, (Convener, MFJCF) initiated the Eye Bank Society of Rajasthan. The groundwork for Organ Donation was laid back then, with people coming forward to support the cause over time.

Ms. Bhavna Jagwani took the initiative to start the deceased organ donation and transplant programme in Rajasthan and set up an NGO named MFJCF in collaboration with MF. The team is continuing their efforts for the noble cause. The team has more than 20 volunteers from different walks of life who work together to do ‘Seva’ for this noble cause. The vision is simple and profound: To give the gift of life through deceased organ donation.

WHERE THE FATHER INSPIRED THE SON



Dr Muneet Kaur Sahi is a medical professional with 20 years of rich experience in Homoeopathic practice, nutrition counselling and social welfare activities. She joined MOHAN Foundation's NCR office in the year 2011. By virtue of her mature approach and years of public life as a doctor she has proved herself to be an invaluable team player in dealing with distressed kin of potential donors and educating lay public in all aspects of this noble cause. Her deep understanding of human nature combined with her effective speaking skills makes her a passionate trainer.

Muneet is a culinary expert, loves to travel and is an avid pet enthusiast. She likes to read mystical books especially autobiographies and has immense curiosity about 'after life' concept.

I HAVE COUNSELLED many families for organ donation in the last seven years but one particular family has a special place in my memory. Whenever I relive those poignant moments, I admire the courage and fortitude of the husband in donating the organs of his wife.

I remember that day clearly, it was June 18, 2014 and the time was 1630 hours when I met Mr Kapoor in the counseling room. "I want to donate the organs of my wife. Her organs are deteriorating. A thought has come to my mind, why not donate her organs and put them to use for others and in turn save many lives." He appeared calm and in control. I was of course speechless and before my emotions got the better of me, I responded by saying that his decision to donate the organs of his wife was really admirable, more so because the gesture was purely voluntary and unconditional.

I then asked him about his wife and he shared with me that his wife was a God-fearing lady. Religion was the focal point of her life and everything else just took its place around it. She was born and brought up in Jalandhar and they had three children, all married and a she was a young 52-year-old grandmother too. While he was telling me about his wife I saw that faraway look in his eyes as if he was reliving those good memories albeit with a hint of sadness. He collected himself and came back to the present. He then requested me not to share this conversation with others yet as he needed time to discuss it with his family, especially his son who was not aware of what was going on in his father's mind. He further added that if required he would take my help in counselling his son.

Next morning I got a call from Mr Kapoor that he would like to meet me along with his son. In the counselling room, Mr Kapoor introduced me to his son and asked him if he had any questions for me. The son looked at his father and broke down. The father with tears in his own eyes tried to console him and said, "If the doctor gives me even one percent hope that your mother will recover, I don't mind staying in the hospital for as long as it takes for this miracle to happen. However, I have been clearly told that we have lost your mother."

I realised that I myself had tears in my eyes. It was heart-rending to witness the father and son consoling each other in their shared grief. I sat there quietly holding the son's hand. No one spoke and no questions were asked. Words seemed unnecessary. One person had brought us together and we were connected. After some time, the son looked at me and said, "I have no problem donating my mother's organs, please go ahead and initiate the process".

Ms. Kapoor's liver, kidneys and heart valves were successfully retrieved. According to her wishes her last rites were performed with her family beside her at her home in Jalandhar though the family is settled in Delhi.

It has been more than four years and I am still in touch with Mr Kapoor. Whenever I have requested him to share the story of his wife in print media or television, he has always come forward and done the needful. He is a strong supporter of the Foundation and its activities and promotes the cause in his community by giving his wife's example.

For his wife he says, "She died early but she had a full life and lived completely. She gave so much in her death as well as she did while she was alive."

The incident made a profound mark on the emotional canvas of my soul. In that moment, I put myself in the shoes of the bereaved husband and felt the multitude of emotions that he was going through and yet dealt with his loss, collected himself and converted it into a tremendous humanitarian gain- all this with little effort from my side. •

IN A FIRST, HEART TRAVELS FROM KERALA TO TAMIL NADU

AUGUST 11, 2015 - it was another routine day for all of us but the extraordinary decision of the father of a young boy made that day special for few of those who were looking towards the mercy of the society delivered on their lives. It was also a landmark day for organ transplant in Kerala as for the first time a cadaver heart was transferred to another state (Kerala to Tamil Nadu).

Pranav (name changed), a native of Kayamkulam, Kerala, was only 19 years old. He had an accident while he was on his bike and suffered serious injury. Initially, he was treated at Medical College Hospital (Alappuzha) where he was intubated and subsequently brought to our hospital for further management.

On arrival, he was initially assessed by the casualty medical officer and it was found that his GCS score was below 5. 'Trauma Alert Team' was called in for immediate resuscitation and care. Doctors from Critical Care, Neuro Surgery, General Surgery and Orthopaedics departments did the primary investigations. A Brain & CT C-spine was done and the



Jacob Mathew A is a Senior Manager – Administration, VPS Lakeshore Hospital, Kochi.

Armed with an MSc in Hospital Management, he has more than 18 years of experience in Corporate Hospital Industry. From 2013 onwards has the additional responsibility for the coordination and counselling in the deceased donor organ donation programme in Lakeshore Hospital.

He received the Best Transplant Coordinator award –Kerala State, from the Chief Minister of Kerala in the year 2014 and The Swamy Narayan award for Best Transplant Coordinator in India from MOHAN Foundation in 2015.

head injury was confirmed and he was taken up for immediate craniotomy and extra ventricular drain (EVD) insertion. Despite providing all supportive measures, no neurological improvement was seen and he developed severe brain stem dysfunction post-operatively and the deterioration continued. His blood pressure was maintained by high doses of inotropic agents. Poor prognosis was informed to father and relatives by the ICU counselor and also by the treating doctor.

The apnoea test was performed and brain stem death was confirmed. As soon as the brain death was declared, there was an emotional outburst as the family couldn't bare the loss of their beloved child. The whole family was shocked and unprepared for such a sudden and untimely death. However, with our help they understood the information given and accepted the finality of the situation.

As per the protocol of our hospital, every case with catastrophic brain injury and a GCS under 8 is to be intimated to ICU counselor for grief counseling. In this case our ICU counselor interacted with the family members and had made a good rapport with them within a day.

Eventually we identified Pranav's uncle as the main decision maker in the family.

While the ICU counselor supported the family, I called the uncle into my office. We offered our heartfelt condolences and eventually introduced the topic of organ donation. We also introduced KNOS (Kerala Network of Organ Sharing). Initially he could not comprehend our request. This proved that public awareness regarding organ donation was not reaching the rural population. After a discussion, which lasted over an hour, he understood the benefits of organ donation and gift of life that organ recipients receive through the donation of deceased organs. He agreed that he will speak with the family and will return with a decision.

After half an hour, the uncle returned to my office along with Pranav's father. They both broke down again. I consoled him and slowly explained to him the need to accept the reality. Towards the end of our discussion, I informed them about statutory procedures and slowly gave him the options of organ donation through Mrithasanjeevani Programme. I observed that Pranav's father was keenly listening, I explained more about organ donation, its processes and what happens to the body during post-mortem (as the case was MLC) etc. I also urged them to think of the nobility of this action. The father, a daily wage-worker, realized that his son's loss was irreversible and agreed to donate Pranav's organs. After counseling, with rolling tears down his cheeks and trembling voice he said, "I have lost my child forever. I don't want his organs wasted on the post-mortem table. With his organs if 5 or 6 patient's life could be saved, I will sign where ever you want as long as it eliminates the suffering of 6 persons. My son will continue living in them". The family collectively consented to donate his organs to eligible individuals listed in KNOS registry awaiting organ transplant

Then things moved fast. I took the necessary signatures in the consent form and alerted KNOS about the potential donor with all available vital signs, laboratory and radiology reports. Within half an hour KNOS came up with the potential matching recipients from the list of regis-

tered recipients. Organs allotment was communicated to me by KNOS Transplant Coordinator and I started coordinating with all the respective hospitals Transplant Coordinators so that the retrieval could be properly planned. Liver and right kidney was allocated to patients registered under our hospital, Left kidney was allocated to patient registered under MCH Kozhikode, spleen & pancreas was allocated to patients registered under AIMS Kochi. However, there was no matching recipient for the heart. I had seen a number of patients getting prepared for a transplant only to find out at the last minute that it was not going to work out. Hence, I called up the nodal officer and requested him to pass on the alert to other state's organ sharing networks so that a precious organ is not wasted.

Time was running out. Finally a matching recipient was found under Tamil Nadu's Organ Sharing Network. The heart patient was admitted in Fortis Malar Hospital, Chennai. The distance would have proved daunting as a heart has to be transplanted within four hours of its being harvested. There is a requirement of "Green Corridor" to achieve this task. I contacted the Transplant Coordinator of Fortis Malar Hospital, Chennai and he informed that they are seeking the options to find an air ambulance for organ transport. Hearing this, I contacted the district administration and the city police. District Collector and the Commissioner of Police offered their full support for creating a green corridor from Lakeshore Hospital to Nedumbassery Airport, which is 38 kms away and takes normally one hour and forty-five minutes in the routine traffic.

After paying tributes, Pranav's body was shifted to the operating theatre for harvesting of organs. Heart & Lung enbloc was packed for transportation. With a police pilot jeep in the front and back, the roads in Kochi were cleared for the ambulance which took just 28 minutes to cover the distance of 38 kms between the airport in Nedumbassery and the hospital in Nettoor. Chennai police and City Administration also ensured "Green Corridor" from airport till hospital. Within 1 hour & 15 minutes, the heart had reached the hospital in Chennai and transplanted successfully to recipient.

With this brave decision, taken by the family, history was created by KNOS. On completion of a year, KNOS organized a Donor Memorial Programme in the state capital where Pranav's family was also invited. The Chief Minister was also present, who hearing this story and those of other donor families, said, "People who haven't experienced something like this, it's hard for them to realize how important the role of a Transplant Coordinator is in organ donation." •

AN UNCONDITIONAL GIFT



Jigisha Yadav is a Transplant Coordinator at MOHAN Foundation Mumbai.

Armed with a Masters in Social Work, she is extremely motivated to work for the welfare of the critically needy persons with dedication and patience. New to the role of transplant coordination, she feels passionately about speaking to the families for organ donation.

She likes watching movies and spending time with her family. She has a seven year old son.

IT WAS A routine morning in the hospital when I received a call from the ICU head of Neuro Critical Care unit about a potential donor. He mentioned on the phone that the patient's wife had been given preliminary information about cessation of her husband's brain functions and that she could consider organ donation. When she seemed inclined to know more, he informed her that he would ask MOHAN Foundation's counsellor to guide her.

I then approached Ms. Anita (name changed) and introduced myself and the Foundation. I began by asking her if she understood what condition her husband was in. From my conversation with her, it was clear that she had accepted the doctor's diagnosis on brain death. She seemed collected and composed. She had a lot of queries on the process of organ donation- how long it would take, whom would the organs be allocated to, which organs would be harvested, etc. Having received all the information, she was ready to go ahead with organ donation. I was relieved that I had been able to obtain the consent with minimal effort on my part. This would be the second successful case in my relatively new role as a Transplant Coordinator. It hadn't been easy so far. In the first few months of my job as a Transplant coordinator, there were multiple potential donors in the ICU; but I had not been able to get many consents. I was beginning to get disheartened. But then came a breakthrough and I facilitated my first donation and this was going to be the second one.

"I wish to meet you again to discuss a few more things", said Ms. Anita on the phone and my heart skipped a beat at that moment hearing her words. Ms. Anita entered the counselling room with a gentleman whom she introduced as her uncle. She further added that he was a close family friend and a neighbour of more than 15 years. "Uncle has liver failure and he is on the waiting list to receive a liver. I am convinced about donating my husband's organs but I want that the liver must be given to him" she said. My heart sank with the way the situation was unfolding, however, I heard her out patiently, without showing any reaction on my face. I was also accompanied by the other Transplant Coordinators of the hospital.

I then explained to both of them that all rights of allocation of organs are with the state allocation agency called ZTCC (Zonal Transplant Coordination Centre) and the allocation is done as per the guidelines laid down by The Transplantation of Human Organs and Tissues Act 1994. This point was driven home with examples of how a well-known politician in Maharashtra couldn't get organs out of turn and how he lost his life while on the waiting list. I kept maintaining eye contact with Ms. Anita and spoke to her earnestly, from my heart.

The uncle seemed agitated and began to grumble that this was not fair. He kept reiterating that he was a close family friend and in spite of the patient's wife wishing to donate the liver to him, he was being denied the same.

I addressed Ms. Anita and calmly told her to take her own time to make up her mind. I then offered her all my help and support in taking this difficult but lifesaving decision. I expressed my limitations in meeting their request and the need to adhere to the guidelines prescribed by the law.

To my great surprise, Ms. Anita announced that she did not need any more time to think, she understood what was being said and was willing to go ahead with the donation.

The heart, liver, kidneys lungs, skin and cornea were donated. More than 8 lives were saved that day. •

KARNATAKA'S FIRST HAND DONATION

HAILING FROM a very poor socio-economic background, Vikas's (name changed) parents came to Bengaluru in the year 2000 in search of work from Bihar. They struggled to make ends meet. They lost three of their children at young ages due to illness and finally they were left with Vikas and his brother. Vikas had to quit studies after class X to start doing odd jobs to help the family and finally got a job as a Sales Assistant in a mobile shop. His father was working as a security guard and mother as a daily wage earner.

Things took an unfortunate turn when 24 year old Vikas, the main bread winner of the family, met with a road traffic accident in the Anekal -Hosur Road on November 15, 2018. He was referred to our neuro team the next day for better management from a small private hospital. Unfortunately, the doctors were unable to save him and he was declared brain dead.

My first conversation with the family was with his father and couple of Vikas's friends. The father broke down in my room and started cursing his fate, "Why am I so unlucky? Why does death chase my family all the time?" I sat there quietly, my heart going out to the weeping soul. He left to join his wife after some time.

Vikas's friends stayed back in my room for few more hours talking about him and remembering him. They shared how lively he was and how he loved cricket. After a while, I introduced the possibility of organ donation and the opportunity to save the lives of many. They seemed a bit uncomfortable initially but heard me out and requested for some time to think



Lija Mol Joseph has over 10 years of experience in the organ donation and transplant program. She has a Master's degree in Social Work and a Masters in Human Resource Management. Currently, she is spearheading the transplant program in Narayana health, Bengaluru, Karnataka

She entered the field of organ donation and transplantation in the year 2006 with the Zonal Coordination Committee of Karnataka (currently Jeevasarthakathe). During her tenure in ZCKK, she was integral part of formulating all policies and guidelines for the individual organ advisory boards and has been appreciated for the contributions to the transplant field in the State of Karnataka.

about it and discuss with the family.

Honestly, I had given up any hope on the family coming back to me as the father was obviously very devastated, especially since he had lost three sons earlier and now he had lost his eldest son in an untimely and tragic manner. To my surprise I got a call from one of Vikas's friends informing me that the parents want to know more about organ donation.

When I met the family, they had many questions such as who will get the organs, how is it decided who will get them, etc. I answered all their queries. The father was extremely emotional throughout the session. Finally, he agreed for organ donation saying, "Let my child live through others. I want to see him alive, I want to see him play cricket and I want to see him enjoy the world again." After I got the consent for all solid organs, I and my team started coordinating for brain death certification and police clearances, since it was a medico legal case.

Few months back I had the opportunity to hear Dr Subramania Iyer's lecture on hand transplantation. I had been very inspired by that session and his sharing of how lives are transformed with the gift of limbs. He had shared the story of this young man who had lost both his hands in an accident and another family's generosity had enabled a double hand transplant.

As I sat in my room, something in my heart told me to explore the possibility of a hand donation. So, with great anxiety and trepidation, I called Vikas's friend once again and requested if I could meet the family again. When I reached their house, I saw the mother lying on the bed and the father trying to pacify her. His friends were sitting quietly. I sat close to the mother and after a few moments, I brought up the topic of hand donation. There was complete silence and I mistook it for a denial. I got up to leave when suddenly the mother held my hand and said, "Take all that is useful for others. We have lost him but let others live because of him." I was left speechless. The father had a few more questions on how the body would look without the hands and I explained that the retrieved hands will be replaced with prosthetics hands. The parents gave their consent. It was a heartbreaking moment for me but this consent from the family became the first of its kind for the State of Karnataka.

Meanwhile, the first brain death declaration was done and Jeevasarthakathe (state body working on deceased organ donation) was informed. As per the protocol, they started searching for recipients for each of the donated organs. Heart, liver and kidneys were allocated to Bangalore zone. An 18 year old girl got the heart, 67 year old male got the liver, a 44 year old got the left kidney and a 55 year old got the right kidney. Lungs were not retrieved as there was no suitable recipient.

The hands were allocated to 31 year old from Panruti, Tamil Nadu through TRANSTAN (State body working in Tamil Nadu).

These were the most heart-wrenching 36 hours of my life, where I went through many intense emotions and broke down many times along with the family.

When I think back, it was not an easy thing for me to do. It was physically, mentally, professionally and emotionally challenging.

The idea of hand donation is new in our country but unless we ask, how will this science develop and progress? Needless to say, the entire process was riddled with a lot of anxiety and reservation on the part of the family, the transplant team, the hospital and most importantly, my own. The organ retrieval teams from various centers of Bangalore were concerned about compromise to the primary lifesaving organs which were more routine procedures with higher success rates. Despite these concerns, the entire team rallied around to make it happen.

Much after the donation, I often relive the distress of the conversations with the family and wonder where they got the strength to take this radical, bold decision.

And as for me, in my work as a Transplant Coordinator, with both failures and successes, this one was by far the most rewarding, even though nerve-racking, experience with a family. No matter how difficult the process, the fight must go on! •

EVERY NOBLE ACTIVITY MAKES ROOM FOR ITSELF

I WAS ON leave, mourning the demise of a very special person- my God mother - and on my way to attend her prayer meeting when I received a call from our Intensivist that there was a potential BSD (Brain Stem Dead) patient in the ICU. He informed me that the first set of tests would start by 12 noon and shared with me that in all probability the patient was brain dead. I turned around and made my way to the hospital.

After reaching the hospital, I took brief details of the patient from the intensivist who was going to perform the tests. From the case documents, I came to know that the patient was a 47-year-old soldier from Kundal, Haryana. He had a sudden episode of unconsciousness with no co-morbidities and during hospitalization was diagnosed with intra cerebral bleed. He had been admitted to the hospital a day prior.

I did some homework and realized that there were hurdles as far as approaching the family for organ donation was concerned, mainly because I was on leave and had had no interaction with the relatives. Things looked challenging but a coordinator never loses hope that is what I have learnt. The tests were done and the relatives were informed that their relative



Lt Col Sandhya V Nair has 22 years of renal transplant and critical care experience in army hospitals across the country. She has been working as a Transplant Coordinator since the last 5 years.

Sandhya has received the Commendation by Army Chief twice in the year 2014 and 2015. She has also received an Award of Excellence in Renal Nursing in the year 2017

Sandhya is an optimistic person who has the ability to handle stress and remain calm in difficult situations. She is a mother of a teenager and loves to dance and travel.

was brain dead.

I approached the family - his wife, brothers and other relatives. I sat next to the wife and introduced myself as the counselor. As soon as I held her hand, she broke down – a sudden outpouring of grief with screams and tears of helplessness. She shared that he was the bread winner of the family who took control of all household decisions whereas she had never even gone alone to the market to buy vegetables. They had two children; the elder one was studying in class XII appearing for the entrance exams and the younger one was in class IX. She kept on weeping as I sat there quietly, listening to her patiently and expressing my understanding and support.

I understood that she was totally dependent on him and was still coming to terms with the magnitude of her loss. I also realized that if at this time I gave her the option of organ donation, she was most likely to refuse. So I decided to give her space and some time to grieve. I explained once again the entire concept of brain death, hugged her and left the room.

At 4 pm, I decided to broach the topic of organ donation with the family and also decided to have separate conversations with the wife and the brothers. I had a half an hour session with the brothers where I found that the younger brother was more approachable and I left with a strong feeling that they would consider the option of organ donation.

I then spoke to the wife and explained to her the condition of her husband and that he had died. She was quiet and calm as compared to the morning counselling session. She heard me and said, "Madam, I have belief in my 'Guru' who has given me holy water to be sprinkled on my husband. There would be a change in his condition." She was also chanting some mantra as advised by her Guru.

I told her that I respected her feelings and told her that miracles do not happen in such a condition and that she needs to find strength from within to get over this terrible loss and think beyond. She said that she wanted to wait till 7 pm and I agreed to her request.

After the last session, I realized that I cannot pressurize her any further and had to give her time to come to terms with her husband's untimely demise. I met the brothers again who by this time were willing to go ahead with organ donation. It gave me confidence to move forward with the case and I took permission from the treating physician to keep the holy water by the bedside of the husband and informed the transplant teams about a potential donor in the ICU.

At 7.30 pm, I mustered courage to speak to the wife once again. I went to her and requested her to give me few minutes and hear me out. I told her that how her 'yes' to donating the organs of her husband could save 5-6 lives and bring joy and happiness to the recipient families. I implored her to think about it and give it a serious thought because at some point in future if she would retrospect at her decision it would give her immense peace at the thought that her husband lives on in many lives.

We spoke for another hour and finally she gave consent for organ donation at 9 pm. Just as she was going to put her signature on the consent form, she paused and said, "If I sign, my children will not forgive me, I had promised them to bring their father as he is. They will not agree, I'm sorry!"

I was quite shook up at this sudden change of mind but somehow managed to collect myself together and mustering my inner strength decided not to give up. With this firm resolve, I requested the wife to let me speak to her children on phone. She wasn't quite sure as she felt they were heart-broken and inconsolable. However, I requested her again to at least let me try and she relented.

I spoke to the children on phone, they were crying inconsolably. I somehow managed to get them to hear me by introducing myself and the purpose of my call. I explained to them the condition of their father and how he can save the lives of many if they give consent for organ donation. To my utter disbelief, the younger daughter after hearing me out, requested me to hand over the phone to her mother. The daughter told her mother, "Mamma, you are doing the noblest thing and we are proud of you and papa". It was the most intensely emotional experience for me. How beautiful that sometimes children teach us selfless lessons of life.

Heart, liver, kidneys and corneas were retrieved thereby giving a new lease of life to 6 people. The heart went to a Jawan from Telangana, liver to a woman from Manipur, kidneys went to women from Kerala and Maharashtra respectively. Indian Army is a shining example of "Unity in Diversity," so rightfully elucidated by one such selfless act that gave life to many others. •

A LIFE ALTERING EXPERIENCE

A UNIQUE and poignant experience one muggy March day in Chennai changed my world view; at once clouding my head with unknown emotions and making me see things crystal clear.

I had only recently joined MOHAN foundation and was in Chennai for a week to attend a training course. MOHAN Foundation is a very unique organisation that has been doing pioneering work in the field of Deceased (Brain Death) Organ Donation in Tamil Nadu and Andhra Pradesh and I had just been given charge to start their north chapter. I was in Chennai to learn about the intricacies of my work as I took it forward.

For those of you, who are completely unfamiliar with this concept, let me quickly try to explain it in as simple words that I can find. Brain Death results from a severe, irreversible injury to the brain or haemorrhage which causes all brain activity to stop. All areas of the brain are damaged and no



Ms Pallavi Kumar has been in the developmental sector for over 25 years and has been associated with many organisations and causes. She started the NCR office of MOHAN Foundation in 2011 and since then has been single-mindedly working for the cause of organ donation. She is extremely motivated about the work she does, especially speaking to families at the time of the loss of a loved one, encouraging them to take the brave decision of donating organs for others who need this life saving gift. Pallavi is an avid reader, an enthusiastic runner and a passionate trekker and recently did the Everest Base Camp.

longer function due to which a person cannot sustain his/her own life, but vital body functions may be maintained by an artificial support system. This maintains circulation to vital organs long enough to facilitate organ donation. The Transplant of Human Organ Act 1994 recognises this as a form of death and allows retrieval of vital organs if the immediate family gives consent.

That afternoon, as I was trying to comprehend a complicated lecture on paediatric brain death, I was called out by one of the MOHAN Foundation staff. I was told that at the Chennai General Hospital (the biggest government hospital in Chennai), the doctors had just declared brain dead a young 17 year old boy from Bihar. The father had arrived a while ago and since the family only spoke Hindi, the counsellor was having a tough time communicating with them. I was asked if I could assist as I knew Hindi. I obviously agreed, though with a lot of trepidation and fear as this was going to be my very first time counselling a family so recently hit by extreme tragedy and trauma.

What transpired at the hospital is something that would remain etched in my mind for as long as I live. I spoke to the father- a frail, old, uneducated, poor man...who had just lost a son who he had after three daughters. And even before he had proper time to grieve, here was a bunch of strangers, in an alien city, asking for his son's organs to save lives of people whom he had never met and never would meet.

Obviously he refused! He said he would like the body back and would like to return home once his son was cremated. Keeping with the norms of organ donation, I told him that we respected his decision but if he could just take 10 more minutes to think about it and then give a final answer. We reiterated, that his loss was irreversible and that no one could feel his pain for him, but that he should once again consider giving this gift of life that could change 7 to 8 lives.

Fifteen minutes later, the father displayed such strength of character and wisdom, that I was moved to tears. He said that he had thought about it and was willing to donate his child's organs provided they went to other poor people like him. Where did he find in himself the strength to take this courageous decision? Where did he find the power to trust a bunch of complete strangers? Where did he find in himself the large heartedness to give so greatly when destiny had been so cruel to snatch away from him something as precious as his child?

It reaffirmed my faith in everything that is good, that is selfless, that is altruistic, and that is humane.....

It reaffirmed my faith in my work.....

It reaffirmed my faith in this world! •

THE MEASURE OF LIFE IS NOT ITS DURATION BUT ITS DONATION

ON A FATEFUL DAY in the month of June 2018, a heart wrenching incident changed the lives of this young couple from Nepal.

Sheela (name changed), after putting her 11 month old child to sleep in the afternoon, got busy with household chores. The child woke up after some time and not finding his mother around, got up from the bed and lost his balance. He sustained a severe head injury and became unconscious.

His uncle immediately rushed the child to the Civil Hospital in Panchkula. In the hospital, he was given the basic first aid treatment and was referred to PGIMER, Chandigarh for further treatment and management.

In PGIMER, the child was admitted in the Neurosurgery Critical Care Unit. In spite of all the efforts of the treating team the child could not be saved and he was declared brain dead by the brain stem death certification committee. The treating physician then explained the irreversible condition of the child to the family and told them that the child was dead.

The parents were, of course, devastated to hear this news. They were both very young (the father was 21 years old and the mother only 19 years of age) – almost children themselves. Losing such a small child, their only child, to these drastic circumstances was something they were finding extremely hard to accept and were hoping for a miracle to happen. Heartbroken, they decided to take the child LAMA (leave against medical advice). The paperwork for LAMA and other formalities like clearance of the dues were completed.

Meanwhile, I received a call from the neurosurgery team informing me about this case. I went to the ICU to meet the family and found the grieving mother with her arms wrapped around her baby. It was a heart-breaking moment and I thought to myself that it was going to be an extremely difficult task to convince this family for organ donation. How does one come to terms with the loss of a baby?

I requested the family to join me in the counselling room. The parents along with the child's uncle joined me. The mother was inconsolable. During the course of the conversation, I realised that the family had accepted the prognosis and the finality of the situation. I felt that I could bring up the option of organ donation. I explained to them that how their little one could save the lives of many other children waiting for a life-saving transplant. On hearing the option of organ donation, the family's ini-



Rajinder Kaur is a Transplant Coordinator at the Department Of Hepatology at PGIMER Chandigarh since January 2015. She has a basic degree in nursing has a masters in Community Health.

Rajinder loves to travel and she also plays the guitar.

tially seemed reluctant and uncomfortable. They were extremely grieved over the loss of their child and were finding it difficult to come to terms with this reality.

Incidentally, the child's uncle had lost his wife a few months back in the same hospital. He had shown a willingness to donate the corneas of his wife but the same could not be retrieved due to some infection. He urged the parents to think about organ donation to save other people's lives. We spoke for some more time and after some serious thought and forgetting their own grief and emotional turmoil of the last few days, the family showed immense courage and decided to donate the organs of the child.

The child was readmitted in the hospital and his organs saved the lives of four patients suffering from end stage organ diseases on PGIMER's waiting list.

Every time I think of the parents and how young they were, it amazes me what a 'grown up' decision they took in their time of immense grief and loss. •

EVERY ACCOMPLISHMENT STARTS WITH THE DECISION TO TRY

"HOW AM I going to restart organ donation conversation with this family" was the first thought that struck me when I met the grief-stricken family of late Ms. Chandra (name changed).

My journey in this programme started when I joined MOHAN Foundation in 2010 as a Transplant Coordinator. I and two of my colleagues were deputed to one of the government hospitals in Chennai as Grief Counsellors cum Transplant Coordinators. Our roles involved counselling the grieving families and facilitating the donation process in the hospital. Having worked as a Transplant Coordinator for a few years in a government hospital, I was then promoted as Programme Manager. As Programme Manager, my responsibility is to oversee the work of Transplant Coordina-

tors placed in various government hospitals and does not include actual ground work. It was a Friday afternoon and I was getting ready for an official meeting. As I was grabbing my papers, I heard the beeping sound from my phone. That was a message from my team from one of the government hospitals stating that there was a young female patient identified as brain stem dead in the hospital.

Since I knew that the first apnoea test would be performed soon and the family would be approached for organ donation, I was regularly checking my phone for updates. At around 6.30pm, there was a message in my inbox - 'Family not willing for organ donation'. I don't know why but I had this strong feeling that I should go to the hospital after my meeting. I called my team and informed them I will be coming to the hospital and half an hour later I was there.

I sat with my team and got an update on the family conversation that had happened so far. My team shared that Ms. Chandra, a loving wife and a mother of two was only 27 years old. On that fateful day, the couple were returning home on their two-wheeler after visiting their relatives. Ms. Chandra, who was sitting behind her husband, fell off the bike as the two-wheeler hit a speed-breaker and sustained severe head injury. After two days of intensive treatment, Ms. Chandra was declared brain stem dead.

When I further probed to understand the family's reasons for refusal, the team shared that no particular reason was given. I enquired as to who all from the family were present in the hospital at the time of first conversation and was told that many family members were there including her husband, mother, brother and other close relatives. However, the husband had walked out of the ICU as soon as the family was informed about the death of his wife. The team had waited for some time for him to come back and since there was not much time left, the team had gone ahead and approached the family for organ donation. The family members had patiently listened to the entire conversation and had said that they would get back after discussing with the patient's husband. Since the husband refused to come up to the ICU, Ms. Chandra's brother and cousins went and spoke to him about organ donation. His reply was a firm 'No' and the family members conveyed the same to the grief counsellors. They also requested the counsellors not to disturb them any further.

I sat down for some time and thought about the information that my team had given me. There were two thoughts that came to me which finally helped me to take the decision to approach the family again and restart the conversation. Firstly, the main decision maker, the husband, was never counselled directly by the coordinators and secondly the other family members seemed fairly open to the idea of donation.

I discussed with my team and decided to approach the family again. I expressed my sympathies at their loss and told them that my intention to talk to them was not really about their decision; but to extend my support in whichever way I could.

I spoke for long with the immediate family and some extended relatives to make sure that they understood the concept of brain stem death and organ donation. In fact they mentioned that donation was not something



Sujatha Suriyamoorthi is working as the Manager - Information Systems (MIS) at the MOHAN Foundation, Chennai. Being a post graduate in Social Work, she started her journey in this programme in 2010 as a Transplant Coordinator with the Foundation.

She loves reading Tamil novels and would love to ride a two-wheeler as long as a green corridor is provided.

new for them as they had donated the corneas of Ms. Chandra's father a few years back.

When I asked why they had refused organ donation, her brother said 'Our life is never going to be the same or whole again; neither of us is able to think anything beyond this immediate loss'. I said that we understood that their life was never going to be whole again but could they do something to find meaning in this loss. We agreed that this may not reduce their sorrow, yet could help them to find a meaningful way to say goodbye to their loved one.

After a long silence, Ms. Chandra's cousin brother stepped in and said "We will try and bring her husband here. Could you speak with him about this?"

It was close to midnight and the ICU corridor was absolutely silent. I was nervous and clueless as to how the husband would respond. Every second seemed like an hour as we waited for him to come.

Our long agonising wait ended when the husband finally arrived in the ICU. After a brief introduction, the conversation was again started but this time I decided to go back to the events leading up to the accident. Finally the husband opened up and started talking about that fateful evening. He shared that after visiting their relatives, they were getting ready to leave but the relatives told them to stay back as it was getting dark. Ms. Chandra seemed unsure and looked at her husband. He was determined to leave and told her to get ready to leave. Ms. Chandra immediately complied and the couple left the place.

"Neither did I listen to my relatives, nor did I ask her what she wanted to do. If I had not decided to leave, she would not have died." As he was saying that, he broke down and tears started rolling down his cheeks. He looked visibly shaken and leaned on the wall for support. He seemed to be guilty of the decision he took and was obviously struggling with his feelings.

As counsellors, we had many aspects to address - his guilt, his grief and finally helping the entire family to take an important decision; all this was immensely challenging. A lot of positive affirmation was given to him to help him to handle his feelings of guilt. He was encouraged to think about organ donation especially in the light of the fact that other family members were open to it.

He asked for some time to discuss with the rest of the family members about donating Ms. Chandra's organs. After an hour's discussion with the family and clarifying their doubts with us about the process, the family took a joint decision to donate Ms. Chandra's organs as well as tissues.

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

Ms. Chandra's kidneys, liver, corneas and heart valves were donated. Yet another remarkable family; yet another learning experience. •

A KING'S FAREWELL

DECEMBER 30, 2014 IT WAS a routine day for 30 year old Arvind (name changed) who was unaware of the surprise party his colleagues had planned for him at his work place in Gurugram to celebrate his midterm promotion. Arvind, who hailed from Hyderabad, had come to Gurugram 5 years back. At 12.30 pm, he suddenly collapsed in the washroom of his office and was rushed to the nearby hospital. He was intubated there and later referred to a super specialty hospital in Gurugram later in the evening. Despite best efforts by the neuro surgical team, he could not be revived and became brain dead two days later.

On January 02, 2015 at 2:30pm I got a call from the neuro-surgeon who had operated upon Arvind informing me that there was a potential brain dead person in the ICU. He further added that he had primed his father about his son's condition and that I should request the critical care team to perform the apnoea test, following which I should initiate counseling for organ donation. The tests were done at 5.30 pm and brain death was confirmed.

I, along with the Program Director and an ICU doctor talked to the family and friends in separate lounge. The family, who had arrived from Hyderabad, was already aware of the cause of organ donation and showed their willingness.

"My son was a very helpful person all through his life and even in his death, he has helped others. The recipients will always remain in my prayers." His mother said, bidding a tearful adieu to her elder son.

The liver, kidneys, heart and corneas were retrieved. One kidney was transplanted in the host hospital. The other kidney and liver went to Army R & R hospital. The heart was to be shared with another hospital in Delhi.

District authorities and the Gurugram and Delhi police were informed to create a green corridor in both Gurugram and Delhi on a busy Saturday afternoon. As the ambulance left the hospital, a police vehicle escorted it to ensure seamless travel via green corridor. A distance of 32 kms was covered in 29 minutes during peak traffic hours.

Gurugram and Delhi were collectively holding their breath. After all, a life was being saved and history was being created – this was the first green corridor of North India.

Within 100 minutes of its retrieval, Arvind's heart was beating in a 16 year old recipient.

When the body was being handed over post retrieval, His mother said, "You have given a King's farewell to my son."

I really salute his parents who have been so brave despite their tragic, irreparable loss. •



Ms. Sukhvinder Lal is a Transplant Coordinator at Max Super Speciality Hospital, New Delhi. She has been working in the field since the last six years and was earlier at Fortis Memorial Research Institute, Gurugram. Sukhvinder has an insatiable appetite for learning and a desire to delve deeper into the entire aspect of donation. She is a mother of a 10 year old daughter and enjoys listening to music.

AISHWARYA'S GIFT LIGHTS UP LIVES



Dr. Sumana Navin has been associated with MOHAN Foundation since 1998 and is based in Chennai. In her present role, as Course Director, she is involved in training Transplant Coordinators and educating healthcare professionals about organ donation and transplantation in India, Bangladesh, Sri Lanka and Nepal. She is the editor of the Indian Transplant Newsletter (since 1998). Her interests are organ transplant ethics, training and education.

THE FIRST THING that I noticed about her was the vibrant blue nail polish on her toes, and then the long braid... Aishwarya was a lively 13-year-old girl, so they all said. And then there were the machines she was connected to as she lay on a bed in the Intensive Care Unit – dead. A sudden catastrophic bleed in the brain, with no warning whatsoever left her brain dead and her family stunned.

Memories, so many of them... yet not enough; these were Aishwarya's mother's feelings. Rama told us with pride that her child would participate in every activity in school, and then murmured brokenly, "She went to school on Monday morning, just like any other day, and now she has returned four days later never to go back again." Her father Prabhakar with tears in his eyes shared that she was the only girl child in his family. An uncle remembered that Aishwarya always had a smile, that she loved to dress up, visit her cousins and play with them. Her friends said that she'd told them that morning that she'd got all that she needed for Diwali and that she was happy.

What struck us when we met the family to counsel them was their unwavering commitment to organ donation. Her maternal uncle said, "We are doing this for Aishwarya...for her life to be meaningful." It meant a long waiting period, more than 24 hours while the procedures were carried out. The entire family waited patiently, stoically till it was all done.

We visited the family on the day of the funeral to pay tribute to Aishwarya. We laid a garland and lit a special candle on which was inscribed "Light...Pass it on." I watched Rama standing by gazing at her daughter's face. Someone had mentioned to me that Rama was a Sanskrit pundit and a long-forgotten prayer from my childhood came to me. I reached for Rama's hand, held it, and recited the verse.

*asato ma sadgamaya
tamasoma jyotir gamaya
mrityormaamritam gamaya
Om shanti shanti shantih*

From ignorance, lead me to truth;
From darkness, lead me to light;
From death, lead me to immortality
Peace, peace, peace



Rama looked at me and said, "Aishwarya too recited that in school every day..."

On Friday 21st October 2016 Aishwarya donated her heart, two kidneys, liver (that was shared by two children) and the corneas (that allowed two people to see again).

Aishwarya passed on the light of life to seven people whose lives were threatened with darkness.

She attained immortality in death.

We pray that her family attains peace.

Source:

Dr. Sumana Navin, Dr. Sunil Shroff. Reminiscences - Aishwarya's Gift Lights Up Lives. Indian Transplant Newsletter. Vol. 15 Issue No.: 48 (Jul 2016–Oct 2016); Available at: <http://www.itnnews.co.in/indian-transplant-newsletter/issue48/Aishwaryas-Gift-Lights-Up-Lives-462.htm>

VOICES



"The vital role of Transplant Coordinators in driving the success and expansion of deceased donor transplant programs has been demonstrated all over the world. From identification, to counseling, to organ placement, to smooth functioning of multi-organ retrieval teams across centers and cities, to organ transport to calming frayed nerves both among the family and the hospital staff, TCs are angels in this divine pursuit that saves lives."

— **Dr. A S SOIN**

Chairman, Institute of Liver Transplantation and Regenerative Medicine
Medanta – The Medicity



"You are the backbone of the transplant programme. You motivate and bring life. You show a way from end of the road to the beginning of a new life to many. You wipe the tears and bring smile to many."

— **Dr. (Prof) ANANT KUMAR**

Chairman
Department of Uro-Oncology, Robotics & Kidney Transplantation
Max group of Hospital Delhi & NCR



"Our Transplant Coordinators in GH (Government Hospital) burnt midnight oil almost throughout the year. They also conducted several awareness programmes in the community. These young people [and other Transplant Coordinators in various private institutions in the state] deserve a pat in the back. Good wishes to all of you, my friends."

— **Dr. J. AMALORPAVANATHAN**

Director (Retd), Department of Vascular Surgery, Madras Medical College and Rajiv Gandhi Government General Hospital, Chennai
Former Member Secretary, Transplant Authority of Tamil Nadu (TRANSTAN), Government of Tamil Nadu



"A Transplant coordinator is a critical link for a successful organ donation and transplantation. According to me, they are the torch bearers of Organ Donation Program and the ray of light at the end of a dark tunnel."

— **Dr. ANIL KUMAR**

Additional Deputy Director General
Directorate General of Health Services
Ministry of Health & Family Welfare Government of India



"The process of organ donation without an effective Transplant Coordinator is like an octopus on roller skates. There is plenty of movement but you never know if one is headed in the right direction! Deceased donation, for some strange reason, tends to happen in the middle of the night or over weekends. Deadlines to be met, aching limbs, no time to eat, frayed tempers, lack of sleep and yet, lives to be saved. In the midst of all this, there is the Transplant Coordinator. A smile on the face, a comforting word, a tender touch, a phone call made, a document filled, a cup of tea provided, a tear wiped and perhaps, a quiet tear shed in the corner with no one watching. Always available. Like the moon on a cloudy night. A light shining through the darkness. In the background, but always there!"

— **Dr. AVNISH SETH**

MD, DM
Director, Gastroenterology & Hepatobiliary Sciences
Director, Fortis Organ Retrieval & Transplant (FORT)



"Transplant Coordination is the bedrock of delivering successful life saving organ transplants. The commitment shown by this truly special group of health workers ensures public faith in organ donation and transplantation."

— **Dr. DARIUS MIRZA**

Professor of HPB & Transplant Surgery
University Hospital Birmingham Children's Hospital, UK
Lead Consultant, Transplant & HPB Surgeon
Apollo Hospital, Navi Mumbai



"It is a well acknowledged fact that Transplant Coordinators form the back bone of a well-organised transplant unit. Interestingly, they are also the face of the transplant unit: the empathy and patience shown by them to the patients who are awaiting transplant go a long way in confidence building for the unit."

— **DR. GOMATHY NARASIMHAN, MS, ASTS FELLOWSHIP (USA)**
Senior Consultant
Liver and Renal Transplant Surgeon
Dr. Rela Institute and Medical Centre, Chennai



"Transplant coordinators are the face and backbone of any transplant program. They wear multiple hats depending on the demands of the situation. They are nurse, social worker, manager, lawyer, doctor, counsellor, friend mixed into one."

— **DR. MATHEW JACOB**
Consultant Hepatobiliary and Multi Organ Transplant Surgeon
Aster Integrated Liver Care, Aster Medcity.
Member Liver Advisory Committee- KNOS
Joint Secretary - Liver Transplant Society of India



"Transplant coordinators are the lynchpin in the wheel of organ transplantation. Whether helping recipients or managing donors they have to bring in a combination of skills including efficiency, empathy and communication to bear during every transplant."

— **DR. PAUL RAMESH THANGARAJ**
Senior Consultant Cardiothoracic and Transplant Surgeon,
Apollo Hospitals, Chennai.

Adjunct Faculty,
Department of Mechanical Engineering, IIT-Madras

"The Transplant Coordinator who is familiarised with the hostile environment of an ICU, will, with grit and experience, become expert in performing the highest level of 'end-of-life care': eliciting organ donation after death."

— **DR. PHILIP THOMAS**
Primary Surgeon, Renaissance Transplant Institute
Doctors Hospital at Renaissance, McAllen, Texas
Associate Professor of Surgery, University of Texas, Rio Grande valley, Texas



"Many years ago when I was learning how to do liver transplants in Birmingham, England I was told by Professor Paul McMaster the senior surgeon there that the Indians in the city never agreed to deceased organ donation. I told him it was because they felt outsiders in the British system and when the law in India was changed they would come forward in droves."

The Transplantation of Human Organs Act was passed in 1994 but even Indians in India did not agree to donate. Till the MOHAN foundation came along in 1997.

There is now, in spite of the very difficult situation here, a turning around and this has been due mainly to the hard work done with so much compassion and care by the Transplant Coordinators of the MOHAN Foundation. Deceased organ donation has increased manifold in the southern and western states and we hope this will soon happen all over the country.

If I had the power I would award the MOHAN Foundation a Nobel Prize."

— **DR. SAMIRAN NUNDY**
Emeritus Consultant
Surgical Gastroenterology and Liver Transplantation, Sir Gang Ram Hospital



"Grief Counsellors and donor coordinators are the best representatives of donor families. The supreme gift of these grieving and bereaved individuals can only be animated and exemplified by them. Their only task must be to ensure that no organ is wasted and every possible life is saved by the gift of organ donation. It is this supreme ideal that every one of these honourable professionals must uphold, despite any duress or external influence. This is the essence of their task; this is the absolute embodiment of a great responsibility."

— **DR. SANDEEP ATTAWAR**
Director of Heart Failure and Transplant Program
Institute of Heart, Lung and Transplantation, Gleneagles Global Hospitals, Chennai



"In my opinion Transplant Coordinators are the backbone of any transplant program - the unsung heroes of transplantation."

— **Dr. (Prof.) SANDEEP GULERIA**
Senior Consultant Surgeon,
(General Surgery, GI Surgery and Transplantation)
Indraprastha Apollo Hospitals



"Transplant Coordinators are the glue that holds the organ sharing system together. It takes a special kind of madness to do this job- long hours, talking to families in their darkest hours, comforting parents, children, spouses and getting them to see the gifts that can arise from terrible tragedy. Not to mention dealing with the logistics of working with multiple teams with tact and diplomacy so the gift of life can be realised many times over.

You all have these Sparks of special madness within you, and we are all the better for it. Thank you"

— **Dr. SONAL ASTHANA**
Senior Consultant HpB and Transplant Surgery
Aster CMI Hospital
Adjunct Faculty, Liver Transplantation, Bangalore Medical College



"Getting hand donated was the greatest obstacle for implementing the first hand transplant programme by us in the country. The Transplant Coordinator team made the impossible possible for us. Working against all odds in a mentally upsetting environment your efforts make the greatest gift of life possible. We are all indebted to you"

— **Dr. SUBRAMANIA IYER**
Professor & Chairman
Plastic & Reconstructive Surgery
Amrita Institute of Medical Sciences
Kochi, Kerala, India



"Title of this compendium "you are the clay, you are the potter" is apt in many ways. Coordinators, I think, display an uncanny similarity to the famous mythical character "Harry Potter". They like Potter, perform magic where normal humans often fail. They, like Harry Potter struggle with difficulties, are disliked and neglected by many, yet they manage to win over adverse circumstances by selflessness and compassion. A coordinator, unlike Harry Potter, is not famous. They indeed are the true invisible wizards of transplantation."

— **Dr. S SUDHINDRAN**
MS FRCS
Department of Solid Organ Transplantation
Amrita Institute of Medical Sciences, Kochi.



"The entire ecosystem on Deceased Donor Transplants happening in India could never have happened but for the army of motivated Transplant Coordinators in our country. They spend hours walking with family members in their times of grief, assisting them and motivating them to donate while at the same time being sensitive not to go to far. I have the highest regard for every single Transplant Coordinator and know that any who had benefitted due to the deceased donor transplants are ever grateful to the donor's family and also to the Transplant Coordinators who played the crucial role at that critical point in time.."

— **P W C DAVIDAR IAS**
Retired Additional Chief Secretary,
Government of Tamil Nadu



"Transplant Coordinators: Brave ... in approaching the family of the bereaved, Gentle ... in holding their hands all the way, Sensitive ... in understanding the gamut of their emotions, Decisive ... in thinking on their feet, Sincere... in their promise to help the dead live on, Leaders ... in the way they coordinate the entire process."

— **Dr. RAMDIP RAY**
Sr Consultant & Joint Director
Liver Transplant & Gastro Intestinal Surgery
Artemis Hospital, Gurugram, Delhi-NCR

VOICES



N V Lakshmi

"Lakshmi had decided to donate her body to a medical institution, in the event of her death about a month before her sudden hospitalisation on 24th May 2011. She died due to cerebral haemorrhage caused by an undetected aneurysm on 7th June 2011 at the age of 52 years.

When we were informed there was no chance of survival, my children insisted we respect her wish. My son in law, a medical practitioner in UK, then suggested the better alternative of organ donation to give a fresh lease of life to terminally ill patients rather than donating the body.

The family, in particular, both our children and Lakshmi's parents, agreed for organ donation without much hesitation. Having had no prior knowledge of such a possibility we did not know how to proceed.

At that hour of grief, my siblings made enquiries and within matter of minutes we had a counsellor from MOHAN Foundation at the hospital. We did not need much counselling regarding the noble act. This priceless donation of her eyes, liver, kidneys and heart gave us some much-needed solace.

I would like to add about the extremely quick response of MOHAN Foundation. It was around 11AM on 6th June that the doctors at Yashoda Hospital Secunderabad had informed us about the inevitable. My brother had immediately contacted his good friend at Guntur, the renowned neurologist Dr Vemuri Rama Tarakanath. It is said that if the desire is strong enough the universe conspires to see it is accomplished. Incidentally Mr Raghuram of MOHAN Foundation was in a meeting with Dr Tarakanath. In a matter of few minutes, the Hyderabad office contacted us and immediately made arrangements for transferring Lakshmi to Global Hospitals, then an accredited hospital to carry out organ donation as per extremely rigid protocol of the Government. MOHAN Foundation were there throughout the night and the next day. This note will be incomplete without expression of gratitude to the empathetic attitude of MOHAN Foundation.

This was covered by the written media over the next few days.

Lakshmi was a wonderful person with philanthropic attitude, which inspired us to continue her good work primarily in field of girl child education & spreading awareness to support organ donation. We have established an NGO N V Lakshmi Foundation and a memorial lecture on her birth anniversary on 13th December to facilitate this work."

— N MOHAN
(Husband)

"I would like to really appreciate your work towards this initiative. I would also like to specially thank Christopher for his help in getting things done at a much faster pace. His dedication, untiring and compassionate approach really helped in facilitating the various steps without too much delay. He was very empathetic and understood the feelings of the family in this situation. Though we could not still get over the loss of our son, but can at least take satisfaction from the fact that he has helped 7 people through his organs and ultimately 7 family members are benefitted from this deed. Without Christopher and your Foundation this would not have been possible in such a short time."

— **Mr. ABHINASH RAMANATHAN**

Uncle of deceased donor Master T. S. Sanjai from Coimbatore about the work of Transplant Coordinator, Mr. Christopher Asir (in an email to MOHAN Foundation dated April 11, 2012)

TRIBUTE TO MS. SAVITA HARISH BY DR. VIDYA VISWANATH LIVING ON...



Ms. Savita Harish

This is a tribute to Savita Harish - a thirty-one-year-old wife, an only child, a cheerful soft-spoken lady, a hard working professional, a friend in need, a cherished daughter-in-law – my brother's wife. In one of those absolutely bizarre vicious moments we call fate, she became one more statistic in the long list of Road Traffic Accidents in Chennai on the 10th of August 2012.

This article is to share my experience of what followed. The prompt response had her in the best super speciality hospital in minutes, and in spite of all the medical intervention and resuscitation, she was pronounced brain dead. Brain death is as complex as it is abrupt. Clinically, it is a decision taken over a set period of time by different neurologists. Emotionally for us, to see her on the hospital bed then, hooked on to tubes which kept her warm and maintained her parameters was agony, to convince ourselves to let go was pure anguish.

In a situation like this, to take a decision regarding organ donation is a very tough one to make for the family. Ethically, the treating physician cannot vocalise organ harvesting at that point and it is the counsellor who helps the family through the declaration, decision making and the severe emotional strain. There is also the issue of where the post-mortem would be done. Here, it was promised that they would be completing the formalities in the hospital premises itself, without transferring her to another set up for the same.

In this time of inexplicable sadness, it was heartrending when my brother and her parents announced, "Take whatever part of her can help another as this is what she would have wanted". They were not medical graduates, but what they did that day and the manner in which they did it was truly humbling.

Watching the team of surgeons and staff poignantly working in tandem with both – the donor and the recipient with total dedication, respect and professionalism through the night reinforced my belief that we had chosen correctly. We did not know nor did we want to know the recipients of her liver, heart valves, both the kidneys and her cornea, but we took refuge in the fact that she was the star who brightened their lives. We

"It has been a year now since my sister-in-law Savita's passing away and I just wrote something about the experience. I wish to express my gratitude to you, your team and the counsellors and surgeons, Dr Khakhar, Dr Manish all of whom I interacted with. I have registered as an organ donor with MOHAN Foundation and am willing to help the cause."

— Dr. Vidya Viswanath
sister-in-law of deceased donor
Ms. Savita Harish
(in an email to MOHAN Foundation dated August 16, 2013).

drew our serenity and solace from the knowledge that this was possible only because she was in the city and the centre which had all its systems in place for multi organ donation.

This experience firmly reinstated my belief that one need not always be a doctor to save lives.

Along with spreading the message of organ donation, it is imperative to develop the right infrastructure to make the procedure accessible and hassle free. We lose valuable organs due to the apprehension and fear of formalities which holds back families from taking the decision. This must be addressed to encourage multi-organ transplants.

Most importantly, we should begin by pledging our organs so that our dear ones do not have to go through the dilemma of decision making for us during this time of extreme distress.

My family's loss is irreplaceable, but today we think of the one we loved - not as a fatal statistic in a road traffic accident, but as one of the 0.08 per million of organ donors we are privileged to have known and as one who is living on...

Source:

Dr. Vidya Viswanath, Dr. Sunil Shroff, Dr. Sumana Navin. Thoughts of a Donor Family LIVING ON... Indian Transplant Newsletter Vol. 12 Issue NO.: 38 (Mar 2013 - Jun 2013);

Available at: <http://www.itnnews.co.in/indian-transplant-newsletter/issue38/Thoughts-of-a-Donor-Family-LIVING-ON-98.htm>

TRIBUTE TO MS. USHA SUDHAKAR BY SUCHITRA SUDHAKAR

ON OCTOBER 2, 1998, on a trip to Pondicherry, the van in which Ms. Usha Sudhakar was travelling had a head-on collision with a bus on the East Coast Road in Chennai.

For her children, Suchitra and Varun Sudhakar, the world came to an end since they had already lost their father in an accident in 1990. 18-year-old Suchitra and 13-year-old Varun took the hardest decision of their lives as the sun went down on their mother in the ICU, to donate her organs and save the lives of others who would otherwise have no hope of living at all.

Suchitra shared memories of her mother at the first-ever ceremony held



Suchitra Sudhakar (Daughter of Usha Sudhakar) at a Donor Felicitation Ceremony organised by MOHAN Foundation

in the country to honour deceased organ donors and felicitate their families on October 30, 1999 in Chennai.

My mother – Transcending human boundaries

“She held my hand when I took my first steps. She picked me up when I fell down and hurt my knee. She scared away the demons and rocked me back to sleep when I’d had a nightmare. This superboddy is none other than my mother - Usha Sudhakar.

Having lost my father at the age of nine, my mother, brother and myself had grown extremely close. My mother adapted herself perfectly to the role of “man of the house and breadwinner” and we moved on. I didn’t mean that we led a bare existence. She toiled hard to see that we led a comfortable life and lacked nothing. Playing the dual role of both mother and father ensured that we never felt the need for anything.

And then tragedy decided to pay our happy home a visit; a visit that would remain branded in our memories with indelible ink.

Anger made my heart and my head scream that a grave injustice had been done. The hands of death had snatched away the wrong person. My mother didn’t have to die. She shouldn’t be the one to die because it was people like her who made the world a better place to live in. Someone up there had made a terrible mistake. But then wisdom took over. My mother had not died. She had just transcended human boundaries. She had transcended human borders. She had moved from darkness to light.

She taught me what it was to be a human being. She had always believed in the giving of herself. And what better way to keep her alive than by donating her organs to those in need.

Having now donated her organs it makes me feel that she is still out there, somewhere, watching over us and guiding as like she always did. Having given so many lives a second chance; she will now live on forever.”

Source:

Dr. Sumana Navin, Dr. Sunil Shroff. HONOURING ORGAN DONOR FAMILIES. Indian Transplant Newsletter Vol. II Issue NO.: 5 (February 2000); Available at: <http://www.itnnews.co.in/indian-transplant-newsletter/issue5/HONOURING-ORGAN-DONOR-FAMILIES-125.htm>

REAL HEROES

These are stories of special people who have not only overcome personal tragedies and time of great adversity in their life but have now dedicated themselves to ease the journey of others facing similar challenges. They have managed to look beyond themselves to contribute something beneficial to the world for the betterment of humanity as a whole.

ANASUYA GUPTA

ANASUYA IS THE Chairperson and Managing Director of CICO Technologies Ltd., a market leader in Construction Chemicals with the oldest brand CICO in the country. An accidental, third generation entrepreneur after the demise of her husband – she leads a pan India Company, which has partnered India’s Infrastructure development and growth since 1930.

Anasuya is a strong advocate of women’s rights, secular beliefs and upliftment of the Micro, Small and Medium Enterprises sector supporting the “Make in India” concept and she carries on her endeavour in each of the above sectors. She started the Amit Gupta Foundation in the memory of her late husband, Amit Gupta, who passed away due to various complications as a result of a renal failure and transplant thereafter.



ANASUYA GUPTA

STORY

RENAL FAILURE IN 1993 was not something that my family was familiar with and certainly did not think it could happen to someone who was only 37 years old. So when in the winter of 1993 my husband Amit was diagnosed with renal failure, we desperately tried to find ways to reverse the system. We travelled to Vellore, Bombay, Madras, Calcutta and London in search of a solution or a method or treatment that would make his kidneys functional. We met the best in the field and were told that the only solution was a transplant.

We held back, still in the hope of finding a way out. We tried alternative medicines - Homeopathy, Ayurveda, Naturopathy, Pranic healing - everything under the sun but the creatinine levels kept rising and while haemoglobin (Hb) kept falling and every other parameter going haywire. Finally when the creatinine soared to an alarming 13 and Hb dropped to 4, we knew we were staring at the worst. Amit was forced into dialysis

– a pre-requirement before renal transplant or when waiting for it. From then on, it was a harrowing journey for Amit, hooked on to the dialysis machine, spending four hours thrice a week in the hospital. Diet played a vital role in rehabilitative care as a well-balanced diet is necessary for patients on dialysis to stay fit as their kidneys are no longer functioning at its full capacity. However, most often patients and families misinterpret dietary restrictions and requirements due to lack of knowledge. The same was true for us as well.

Some patients adjust to dialysis – my husband did not. It was increasingly becoming clear that the need of the hour was a kidney transplant. We were by now beginning to resign ourselves to this reality. It was important to do everything in our capacity to save Amit. We had two small children and a business to run where the employees were dependent on him.

There was no one in the family who could have donated a kidney – Amit's mother was highly diabetic and a heart patient, his elder brother had similar conditions, Amit had already lost his father and I had a different blood group. I had the challenge of being the main caregiver for Amit and to parent our two children both below the age of ten. Amit was the only bread earner for our family and it was imperative for him to get well.

The State of West Bengal supported me in my endeavor and we found a willing, unrelated donor, who was known to another patient undergoing dialysis. This gentleman too had a young family, which needed to be saved. Fortunately the Transplant Act had not come into force. I use the term "fortunately" as it removed one extra battle front for the family who were

fighting many battles at the same time. There were murmurings of misdeeds and exploitation of the innocent poor and unaware, wherein both Central and State Governments were debating this law. Once the formalities were completed with everyone on board – the patient, the administration, the hospital, the doctors, the families, we went ahead with the surgery.

As a recipient's relative, I would like to emphasize an important point here. It does not end with getting an organ. Organ transplant is a lifelong commitment to medication, lifestyle changes and a disciplined life. A transplant also does not come cheap. So while we make sure we enable the gift of life – the

coordinators, the doctors and all stake holders must ensure that this point is made amply clear. I am glad that we are raising this bar of awareness for the need to donate our organs after our death. However, a lot has to be done. Our organ donation rates are way below our target. Brain-death, leading to cadaver transplants, is not understood in India making the job of Transplant Coordinators really tough and emotionally challenging. My husband passed away in 2008 due to various complications as a result of renal failure and transplant thereafter. In the 15 long years that he was under treatment, I had first-hand experience of the despair, trauma and inadequate knowledge of both patients and families suffering from end stage organ failure. As a

***“We, at the Foundation
do our bit with huge support
from MOHAN Foundation
but I would like to do more
to make a difference.”***

family, each time we were surprised with new ailments which we were not prepared for by the doctors. So it was always fire-fighting instead of taking preventive measures. Here too, both coordinators and doctors play a vital role to ensure good health post-surgery.

In memory of my husband, I started a Foundation called Amit Gupta Foundation to raise awareness on organ donation. Our main aim is to speak to congregations in corporates, schools, colleges, institutions, NGO's, and police stations to make them aware of the importance of pledging organs. I live in the hope that one day the Government will make each donor card legal and thus on passing, the registry system will automatically recognize this wish and therefore give other people waiting to live a full life an opportunity to do so. I know now many organisations have come forward to push this agenda, but the Government needs to step in aggressively.

The Foundation also engages with patients and families with end stage organ failure in counseling, advice on diet, medication, costs involved. Most of the people in need of this counseling are from less privileged or uneducated backgrounds. They need to be directed in the right path. More often than not the confidence they get out of this learning helps them to tackle problems and find solutions.

"We, at the Foundation do our bit with huge support from MOHAN Foundation but I would like to do more to make a difference."

ANIKA PARASHAR

ANIKA HAS OVER 18 years of experience working with reputable organizations such as Fortis Healthcare, Mahindra & Mahindra, The National Childbirth Trust, BSKYB, Channel 4 and Old World Hospitality, to name a few. She has been creating innovative brands in women care and women's health in India for the past decade.

Anika is the founder of ORGAN – Organ Giving and Receiving Awareness Network, which spreads awareness about Organ Donation and Transplant. Apart from connecting recipients to donors and engaging in large-scale awareness campaigns, they have launched India's first Transplant Guide, which is an all-inclusive virtual handbook of all transplant centres in India, along with lots of related information a transplant patient may require.

However, her biggest qualification is she is the mother of Nirvaan and Inayat who continue to inspire and motivate her everyday. Anika enjoys writing her blog <http://www.unapologeticme.in>, playing the piano, painting, cooking and dreaming....

STORY

ORGAN DONATION is a very personal issue for my family. My maasi (mother's sister) had a heart transplant 17 years ago in the US and lived for 14 years until she passed away after a second heart transplant 3 years ago. In 2012, my beloved mother, Late Ms. Kirti Parashar was told that she



ANIKA PARASHAR

“A very brave and bereaved family blessed my mother with the gift of life for five years. We can only hope that our work can inspire all of us to do the same.”

needed a heart transplant. She had cardiomyopathy, a condition where the muscles of the heart weaken and eventually leads to heart failure. Over the years, we discovered that several others in the family have the same disease.

As a family we had no idea where to begin – we didn’t know where to go, how to get on a waiting list and how to go about looking for a donor in India. Unlike her sister, my mother was unwilling to uproot her life and go to the US to get a transplant. She preferred to be here, surrounded by her friends and family. So in 2013, my brother and I started to look for options in and around our hometown Delhi. We were shocked to learn of the ground reality. Although there were fantastic surgeons and good hospitals in Delhi, there were hardly any deceased donations happening in the city and there was no system in place to ensure that if and when an organ was available, it would be optimally utilised. We were advised

by many to move to Chennai, as Tamil Nadu as a state had the highest number of deceased donations happening and had one of the most organised organ transplant networks in the country.

On December 13, 2013, thanks to the generosity of a grieving family who consented to organ donation, my mother underwent her heart transplant.

As this cause was so close to our hearts, I wanted to do something about the apathy towards organ donation and the lack of awareness. We did not want others to suffer the same frustration and helplessness that we felt. We have committed ourselves, through our family foundations- The Parashar Foundation and The Vijaya Gujral Foundation - to work towards improving the organ dona-

tion landscape in India.

The Organ Receiving & Giving Awareness Network (ORGAN) India was created as an initiative of the Parashar Foundation in March 2013 with the goal of raising awareness on organ donation and to educate those suffering from organ failure and help them in their ordeal by offering information, advice and counselling.

Although there are excellent surgeons and fantastic hospitals with brilliant infrastructure and technology in most places in the country – there are very few organs available for transplantation. Why is there such a huge shortage of organs in a country of 1.3 billion people? Too many reasons to count. We don’t know enough about deceased organ donation to be able take a stand and pledge our organs. We don’t know what the process is or what will happen after we sign a donor card. We have no clarity on when organ donation can happen, on what is brain-death, and what happens to us once brain death is declared. We worry about hospitals not working hard enough on us simply because we have pledged to be organ donors. There is no clear directional information which tells us which hospitals perform transplants, who the surgeons are or where we can sign up as potential organ recipients. It is difficult to even figure out where to register and pledge our own organs for donation.

The mandate was simple – we would fill the gaps in India’s organ donation ecosystem. All initiatives that have been undertaken by ORGAN India have been done so, after it was evident that there was a need for them across the country. Below are some of our most important initiatives.

- Transplant Guide & Helplines
- Body Donation Directory
- Information Dissemination, Blog, Films, Pledges
- Let’s Get ORGANized School Campaign
- Social Media Campaigns
- Collaborative Conclave for Organ Donation

My beloved mother, who lived with such dignity and grace despite many challenges she faced in her life, passed away in November 2018. She would have completed the fifth year of her new life if she had lived another month. We are devastated by her loss but we feel blessed and lucky to have been given our mother for an additional five years thanks to her heart transplant. We were blessed to be able to help her take her first breaths, her first sips of water, her first morsels of food, her first steps as she began her second life.... How many children have been lucky enough to say they helped give life to their mother?

My mother was a silent rock. She was extremely quiet but her resilience and determination coupled with her softness and grace made her a force to reckon with. As a mother, she was always available, always present, always supportive. She raised me to believe in myself in my capabilities and my unlimited potential and no matter how far I went from being the daughter she could understand easily, she expanded her horizons to grow with me and embrace who I became. Ma’s silent and steady presence in my children’s lives, gave Nirvaan and Inayat a second parent these last five years when my marriage broke down and I believe it was for us that she survived, that she fought and that she lived with gusto during this second innings.

What amazes me is the fullness of life she was determined to live post losing my father who really was her world. She was the strength of this family. She was the ambassador for Organ Donation and Transplant for the NGO we started to help others in gratitude for her survival. She was an enthusiastic bridge player, a keen traveller and she loved her time with her friends.

A very brave and bereaved family blessed my mother with the gift of life for five years. We can only hope that our work can inspire all of us to do the same. Sometimes it is through personal pain today, that you can make a better tomorrow. We hope we can make that impact.



Dr. Anita Hada Sangwan

ANITA HADA

ANITA IS ASSOCIATED with First India News, Rajasthan and is also an Assistant Professor in IIS University, teaching English literature part time. She gets her satisfaction from contributing towards the cause of Organ Donation under the umbrella of Navjeevan- MFJCF.

She is a published author, writing stories, articles and poetry in both English and Hindi. She is also a resource person with Rajasthan Police Academy.

STORY

WE SEE OUR today and plan our tomorrows but God in all his wisdom sees our tomorrows and beautifully plans our today.

This, I think perfectly defines my journey.

My journey with organ and tissue donation started when Mr. Jagdish Chandra (CMD, First India News) asked me to join ETV Rajasthan as a talk show host. My second show was about eye donation and my guests were Ms Bhavna Jagwani, Mr Ravi Kamra and Mr J K Jaju from Jaipur Citizen Forum (JCF). I told Bhavna that I was keen to pledge my eyes. Bhavna, with all her positivity and charisma, had drawn me into the cause even before the interview began. She became my Guru in this journey.

My journey that started with eye donation soon moved into organ and tissue donation when JCF partnered with MOHAN Foundation (MF) to create MFJCF and I became a part of team of volunteers who flagged

off this initiative in Rajasthan so that the benefits of organ donation and transplant could reach one and all. Meanwhile life had other plans. In 2014, my son was diagnosed with Chronic Kidney Disease brought on by Glomerulonephritis. Life changed for us as we grappled with the reality and sought medical advice from experts. My son Ashish bravely accepted the lifestyle changes with a positive attitude. Things started deteriorating rapidly in June 2017 and till June 2018 there was not a test we did not go through, a doctor we did not seek or a God I did not pray to.

As the creatinine rose, we started thinking of transplant and with the Creatinine touching 10 within a span of 2 months; under the advice of Dr. Sunil Shroff (Managing Trustee, MF) we decided to go in for a pre-emptive transplant. Dr. Shroff referred us to Dr. Anant Kumar at Max Hospital, Delhi. After much deliberation, a transplant was scheduled.

On August 16, my son was reborn. He underwent a kidney transplant. I was the donor. Initially it was difficult for me to convince Ashish that I should be the donor. He was reluctant to make me go through pain and surgery for him. I, on the other hand was absolutely sure about my decision. My confidence came from my knowledge and my experience in this field. My sewa for the cause of Organ Donation had prepared me well.

I strongly believe that if there is an option of a suitable donor within

“Today, I am healthier and happier than before, as I see my son getting better each day and living life the way he should. And I am more determined to improve the organ donation scenario in Rajasthan.”

the family, the same should be explored. Organs from deceased donation should be left as an option for those who do not have any other alternative. We have thousands of patients on the waiting list, waiting for a lifesaving transplant. They have to be helped.

My husband is also associated with this work and totally supported my decision. Together we will continue to contribute to this cause. There are so many people I would like to thank but what I am most thankful about is the fact that I was aware and knowledgeable enough to take this decision. It is a lack of awareness and information that leads to fear and indecision. I remember sitting in the hospital waiting room with another mother who was very scared, though willing to donate. I shared my experiences with her and helped her feel reassured. Keeping faith, being positive, having a sense of humour and being aware – all this has helped me in my journey from working for organ donation to being a donor myself.

Today, I am healthier and happier than before, as I see my son getting better each day and living life the way he should. And I am more determined to improve the organ donation scenario in Rajasthan.

And Ashish always says, “Mummy, you gave birth to me twice.”

C Y PAL

C Y PAL HAS NEARLY 50 years of experience with the corporate sector - 17 years in Hindustan Unilever Limited followed by a long tenure of 38 years with Cadburys. He retired from his executive role as MD in 1997 and continued as non-executive Chairman of the company till 2015.

He is a director on the Board of three companies viz United Breweries, Sriram Pistons and Infiloom and has been actively involved with many Industry Associations.

Besides his passion of helping the poor through ‘Transplants Help the Poor Foundation’, he is a regular with yoga and spends a better part his free time with his two grown up daughters and son and 6 grandchildren.

STORY

THE BACKGROUND: My story goes back to 1983 when my wife Pratima’s routine blood tests indicated slightly raised liver enzyme levels of around 100 leading to many visits to various doctors to identify the cause. One doctor suggested doing a biopsy of the liver which was done in a renowned hospital but conclusion could not be reached because the biopsy sample was found to be insufficient to determine the cause.

Since Pratima’s quality of life was not really impacted, we almost forgot about the bad experience of the biopsy and an inconclusive result and moved on. She was full of life and very energetic. She was far too busy raising three growing children to really think of her health and the raised enzyme issue.



Mr C Y Pal

I have always had a desire to give something back to society but after my wife passed away, I was inspired to do something concrete in the area of transplantation.

However, after about 10 years or so, we began seeing some signs of liver related problems. The doctors introduced us to new term called 'ascites'. Unfortunately, back then we did not have the advantage of the handy 'Dr Google' to explore the terminology and learn more about it.

In 1994, we were advised to get various scans done and the results shocked us. Pratima had cirrhosis of liver. We visited more specialists and soon one of them broke the unnerving news that the only way forward

was a liver transplant. Many more investigations followed and it was established that the cirrhosis in Pratima's case had been caused by Hepatitis C which obviously came into her blood stream because of blood transfusion given to her during one of the gynaecological surgery she had in 1978. Unfortunately in those days there were no stringent processes on donated blood to rule out infections. The virus had taken 15 years to reach the stage of cirrhosis of liver in Pratima.

I frantically started reading on this and talking to specialists to learn more about liver transplantation - how and where can it be done, its implications, long term prognosis and most importantly, the need for an organ donor.

I further learnt that liver transplants in India in those days were at a very nascent stage and being a major surgery it had a long way to go to get to the stage where it is today, as we now have many good liver surgeons and transplant centres in the country.

Managing the liver transplant

Being from Cadbury, I knew Birmingham (the International head quarter of the company in those days) well as I would travel there very frequently for work. With the help of my colleagues there, I discovered that Queen Elizabeth Hospital in Birmingham is a major centre for liver transplants. In 1995, I decided to take my wife to Birmingham to explore a liver transplant for her. There was great support from my company in every way possible. I kept myself busy with work while we waited for my wife to get a deceased donor. Her transplant finally happened in early 1996 and we came back to Mumbai after she had stabilised. After living a fairly full life for 20 years, Pratima unfortunately passed away in July 2016. During this period I took Pratima to Birmingham many times for check-ups or for dealing with minor problems and this gave me the opportunity to interact with a lot of experts which added to my knowledge about liver transplants.

My greatest Support - Dr Darius Mirza

One of my greatest privileges during this period was my association with Darius Mirza. When I first took Pratima to Birmingham for the liver transplant, a very good doctor friend from Mumbai suggested that I meet this young doctor from Bombay who was working in the Queen Elizabeth Hospital in Birmingham. My getting to know Darius since then has been the greatest boon of my life because in him I found not only a great surgeon with high commitment but also a wonderful human being.

Setting up of Transplant- Help the Poor Foundation

I have always had a desire to give something back to society but after my wife passed away, I was inspired to do something concrete in the area of transplantation. With Darius Mirza's enormous help, guidance and support we set up a Foundation called 'Transplants Help the Poor' Foundation in 2017. We have five well known trustees and Darius Mirza is decidedly the most important trustee we have. He is actively involved in all that we do.

The Foundation is focussed on providing financial help for liver, kidney and heart transplants and in a span of 18 months since its inception we have been able to help 25 patients - 18 (including 5 children) for liver transplant and 7 for kidney transplant. We are registered with the Charity Commissioner in Mumbai and have a 12 AA and 80G clearance for income tax exemption for donations to our Foundation.

We run a program called JEET (Joint Effort to Enable Transplants) and have developed working contacts with Rotary International, Maharashtra Government and many others NGO'S and Foundations so that we can collectively work towards saving more and more lives of poor and underprivileged people through transplants. While our current activities are more in Maharashtra our vision going forward is to extend our activities, as our resources grow, to all over India.

DR. RAVI WANKHEDE

RAVI IS THE Honorary Director and Centre Head, He is a former Indian Air Force doctor, having put in eight years of service to the Nation, before settling down in his native town Nagpur.

He has been associated with MOHAN Foundation for over 7 years following his voluntary kidney donation to a friend in 2009. Ravi's act of donating kidney to a friend at the age of 60 attracted a lot of media attention after which the Government of Maharashtra nominated him as an expert member of the Zonal Transplant Co-ordination Centre (ZTCC) - Nagpur. This has led him to initiate mass awareness campaigns in and around Nagpur. Ravi has worked with the Academy of Medical Sciences, Indian Medical Associations, Indian Society of Critical Care Medicine, Central India Kidney Foundation, Rotary Clubs, etc. for conducting awareness sessions and seminars on organ donation.

STORY

IT IS EARLY 2009. My dear friend since school days, Salim Chimthanawala, has just been told by his nephrologist that he is suffering from CRF (Chronic Renal Failure) and has been advised a kidney transplant at the earliest.

Salim is put on dialysis, a cumbersome process and a temporary measure, till the time he is able to get a suitable matching donor. In a family where a kidney transplant is required, it's not just the patient who suffers,



Dr. Ravi Wankhede

but the entire family gets unsettled. People come forward with all sorts of alternatives, except offering to donate. And that's understandable. The Government rules for living transplantation are stringent as it allows the first relations to donate without much of hassles but anybody outside of the relationship has to go through a rigorous exercise to prove that the donation is not for commercial reasons.

Till about a year ago, Salim was leading a very healthy and active life. He has always had an amazing circle of friends – within Nagpur and around the world. He has always been someone who was willing to help anyone, anytime of the day or night. When I was serving in the Armed Forces, he took care of my parents and sisters. After I came back to Nagpur, Salim helped me start a Blood Bank and was also the first donor of the bank.

One day Salim and his wife Sakina came to meet me. Both were unusually quiet. When asked, Salim told me that the Nephrologist has advised a transplant immediately. He told me that they had failed to find a suitable donor within the family and this was causing them a lot of anxiety. Somehow, it did not even take me a moment to offer to donate my kidney if it was found to be matching. The thought came to me most naturally. I noticed Salim and Sakina's eyes getting moist but they kept quiet. I broke the silence and told them I will speak to Dr. Sameer Chaubey the Nephrologist and see how to take this forward.

After they left, I called up Dr Chaubey and conveyed to him my intentions. He asked me to give my blood sample for blood typing, tissue typing and cross-matching with Salim's blood. By evening, I found out that the results showed that I was a matching donor. I felt euphoric. I immediately called Salim and shared the test results. His emotional response was, "If your blood had not matched mine, I don't know whose would have."

In the evening I informed my wife, Kiran. She put up a brave face and asked, "Will it be safe for you?" I smiled at her and told her that even I was not much aware about how things would work out.

After two days Salim and I went to see the Nephrologist who told us that an unrelated organ donor had to undergo several clearances as required by the law. One had to prove his/her identity from the police station, get a psychiatric evaluation, submit copies of Income tax returns, give affidavit on oath in the court the reason for donating the kidney etc. Basically the law would try to rule out any coercion or monetary exchange and establish that the donation is purely out of affection and attachment.

I had to undergo a complete health check-up as I was nearly turning 60. All my test reports were within normal parameters including the renal angiogram. I was especially anxious about this test but when the radiologist told me that my kidneys were perfectly healthy, I felt relieved. I spent few more hours in the hospital resting and the next morning I was up and about.

The next couple of days were very hectic for me, as we went about completing the medico-legal formalities. It included a visit to the police station for personal verification/identification (in those days there were no documents like Aadhaar Card). The police inspector was also confused as to why am I getting the verification done. After I explained to him my

reason, he understood and fully cooperated and gave the verification certificate. I also got a psychiatric clearance done.

We (my wife and myself) also informed our sons and their spouses about our decision to donate my kidney to Salim. My elder son Gaurav is with the Royal Australian Air Force and my younger son, Gautam is a medical professional practicing at Gurugram. Both respected and supported my decision to help Salim uncle as they too were very fond of him.

Other formalities included visiting the district courts and submitting my income-tax returns of the last 3 years. There was lot of paper work and I had to affix my signatures at various places which was quite tiring.

Having completed all the necessary paperwork, I was given a date to appear before the Authorization Committee. I vividly remember that it was a very hot day in the month of May and summer was at its peak in Nagpur. Salim, Sakina and I were all sitting in the corridor outside the Dean's office where there were no fans and no provision for drinking water. We were then called to the Dean's air-conditioned office, so we got some relief from the oppressing heat. We were called in one at a time. Salim was called first, then Sakina and I went in last.

I saw familiar faces sitting inside in the committee. Belonging to the same fraternity I recognized few of them but there were no informal exchanges, it was strictly professional. A video-cameraman was recording the proceedings as mandated by the law.

My wife was called next. When asked, "Don't you think your husband is taking undue risk at 60 years of age?" she replied, "I have complete faith in my husband's decision. It is a well thought out decision. He has undergone all the necessary medical tests and he is a fit donor. Salim is a close family friend and I support and respect his decision."

Next day, Salim called me to inform that the Authorization Committee had granted the much-awaited permission. The date of the surgery was fixed for May 26, 2009 at Suretech Hospital, Dhantoli, Nagpur. Both Salim and I were admitted in the hospital on May 25, 2009. Lot of our well-wishers came to the hospital to offer their support and good wishes. Before retiring for the night, I went to meet Salim in his room to wish him good luck for the surgery. It was a very emotional and touching meeting.

May 26, 2009 – on the day of the transplant, Salim was taken in the pre-operative room for preparation for the surgery. We wished each other without the usual hug. We did not feel the need to say anything, words were not needed.

I requested for some time before being shifted to the operating theatre because I wanted to meet my son, Gautam who was reaching Nagpur from Delhi. I spent few minutes with my son and also spoke to my elder

“ It has been a wonderful journey that started in the year 2009 with a single decision I took of donating my kidney to a friend. I sometimes wonder, had I not taken the decision to donate my kidney, would I have ever discovered the joys of working in this field and the miracle of organ donation. ”

son on phone. After speaking with my sons, I felt calm and relaxed and my morale was at an all-time high.

I was wheeled in the pre-operative room for the surgery preparation. I was given spinal anesthesia followed by another intra-venous shot in my forearm that put me to sleep. It was early evening when I regained my consciousness with some kind of pain in my right flank (right kidney was retrieved and transplanted). My wife and my sister were sitting beside me in the hospital room. I asked them about Salim and they informed me that he was doing well. I was then given a pain killer for the pain in my right flank following that I slept peacefully and woke up next morning feeling better. After 4 days, I was discharged from the hospital. Salim had to stay longer as he had to be stabilized on a multitude of drugs.

Many local and national dailies and TV channels covered this story. Most of the focus seemed on how I had stepped beyond religious boundaries and donated my kidney to Salim. In truth, Salim was a dear friend and his religion was of no concern to me. I would have done that for any friend of mine.

I joined the blood bank after 15 days as I was feeling rested and healthy. Salim was also discharged from the hospital around the same time and his health also improved gradually.

One fine day I received a call from the collector of Nagpur informing me that he had received a call from Mr. Ravindra Jadhav, Personal Secretary of Smt. Pratibha Devi Patil, the then President of India, who after reading about this had expressed her wish to invite me to the Rashtrapati Bhavan. I was speechless on hearing this but soon regained my composure and accepted the invitation. I further added that I would like to be accompanied with Salim and his wife but as he is still recuperating, the visit could be delayed. I was told that Mr Jadhav had left the decision to me as to how and when I want to visit Rashtrapati Bhavan.

On February 25, 2010, exactly after 8 months of donating my kidney, we visited the Rashtrapati Bhavan. It was a significant day in my life. I was accompanied by my wife, both my sons with their spouses and my granddaughters. We met Smt. Pratibha Devi Patil, the President of India who told me that I had carried out a very commendable act of saving the life of my friend by donating my kidney to him. She further added that she had recently mentioned about this noble act in one of her speeches during an award ceremony at Vigyan Bhavan, Delhi.

The President spoke to each one of us. She also spoke to Salim and enquired about his health and told him to look after his new gifted kidney. We spent close to 30 minutes with her. This incident has left a lasting impression in my mind.

Innumerable awards and felicitations continued to pour in from in and around Nagpur. A lot of awareness activities had started to generate interest in organ donation in the country. Around this time, I read an article about MOHAN Foundation - an NGO working towards facilitating donations from 'brain dead' people i.e. deceased organ donation. I searched the net for more information on the Foundation and came to know about the good work they were doing. I sent a mail seeking more information.

I also mentioned in my mail that I was a kidney donor and that I had donated my kidney to a friend. Within a day, I received a reply from Dr. Sunil Shroff, the Managing Trustee of the Foundation. He invited me to attend their annual conference being held in Hyderabad. The workshop was an eye-opener for me as it gave me an insight into deceased organ donation, besides giving me detailed information on transplant coordination and grief counselling. In the workshop, I also met several prominent doctors, and Transplant Coordinators working in the field of organ donation and transplantation from across the country. There and then I decided to join MOHAN Foundation and work for this most important but underplayed out cause in our country.

After coming back to Nagpur, I came to know that the Transplant Coordinators working in the Hospitals were not trained for the purpose of counselling for organ donation. This was perhaps one major reason why there were no deceased organ donations taking place in Maharashtra more so in Nagpur. Meanwhile a body called Zonal Transplant Coordination Center (ZTCC) was established by the Government of Maharashtra at Nagpur and I was appointed an expert member of the Center. Gradually things started to take shape in Nagpur with me organizing the first Transplant Coordinators Training in collaboration with MOHAN Foundation. And, in July 2013, MOHAN Foundation's Nagpur office became operational with me as the Honorary Director. In the last 5 years, we have had 38 successful deceased organ donations benefitting 40 people getting kidneys, lung, heart, liver and tissues.

It has been a wonderful journey that started in the year 2009 with a single decision I took of donating my kidney to a friend. I sometimes wonder, had I not taken the decision to donate my kidney, would I have ever discovered the joys of working in this field and the miracle of organ donation.

JAYA JAIRAM

JAYA IS THE Project Manager at MOHAN Foundation office in Mumbai. Equipped with an engineering degree and a post-graduation in MBA, she has worked in the corporate sector for 18 years. After she underwent a kidney transplant in 2010, she began reading more on the many lives being lost for want of a life-saving organ and strongly felt that she had to do something about it. She started the Mumbai Chapter of MOHAN Foundation in 2016.

Jaya is a blessed mother of a teen and loves her work. She likes being surrounded by peace and nature. She loves and values her 'me time' and is very grateful for her second chance and has been working at 'ticking off' things on her bucket list.

STORY

"MY MOTHER, sweet mother. You always care for me and my family. I and my family love you very much. We also want to help you always. We



Jaya Jairam with her mother.

want (you) to be well, never fall ill. You will be well (and) back soon. We want this only”.

These innocent, endearing words written by my 5 year old daughter blurred my vision as tears filled up my eyes. She must have kept the note by my pillow while I was asleep. The tears fell on the little doodled sketches on the piece of paper. What must be going on in her mind, I kept thinking...

It is an honour for me to have the opportunity to share my transplant story. There are so many that don't live long enough to share theirs.

In 2008, at the age of 33, the symptoms had begun to appear but they were so disconnected that even my family doctor could not put them all together. I had lost around 8 kg in 9 months, had developed plantar fasciitis in my left foot, had a sudden deterioration in my left eye vision, my teeth were beginning to yellow and very often, I would feel feverish in the evenings, with no energy left in me. Quite anxious about my health issues, my husband suggested that I get a complete check-up done.

In April 2009, tests revealed elevated creatinine levels and high blood pressure. I was referred to a nephrologist. I went alone as, honestly, at that point I had not anticipated anything serious. After a whole battery of tests and a kidney biopsy, I was informed that I was suffering from chronic renal failure and that my kidneys were functioning at less than 10%. I was shocked and in denial. I had no typical signs like swelling or reduction in urinary output. I had never suffered from any major illness in the past.. How could this be happening to me? Why me, my mind asked.

I was immediately put on leached, low salt food. The nutritionist gave a long list of dos and don'ts. Meanwhile the creatinine levels kept rising. No medicines or dietary changes were helping to stabilise it. When it crossed 6, I was asked to get ready for haemodialysis by getting a fistula done. The word 'dialysis' snapped my already fraught nerves and sapped me of my remaining will and I did the most illogical thing i.e. refuse the fistula. I did not want a life-long reminder! I started reading about peritoneal dialysis and somehow felt that it gave more freedom - to be away from dialysis centres and to be able to get the dialysis done while working. The very thought of haemodialysis made me feel helpless and I hated the feeling.

Creatinine levels kept rising and were hovering around 7 by the November of 2009. I would be hit by waves of nausea. Every time I took a deep breath, I used to get the smell of ammonia, which would sickeningly remind me of a public urinal. I was frustrated with the diet restrictions and the huge amount of medicines and the frequent visits to the doctors depressed me. I couldn't even take a few steps without feeling breathless. I was losing my enthusiasm for life and began avoiding people.

Dilemmas & Discussions: On one of those days when I was feeling extremely troubled and dejected, I was talking to my husband about how my entire life centred around my illness – frequent visits to the nephrologist due to one or the other nagging health issue, getting erythropoietin injections repeatedly, checking the parameters every week and how morbid thoughts had begun to occupy my mind especially my constant fear – whether I would live to see my daughter grow. Suddenly, my husband said that we should explore the option of kidney transplant and that he wished to donate one of his kidneys to keep us together and happy. I was

overwhelmed with emotion.

He broached the subject with the doctor, who in turn said that I could have a pre-emptive kidney transplant; however, the graft survival would definitely be better if it were from a blood relative.

When they heard this, my father, mother and brother – all volunteered to be donors. I felt blessed and was overcome with gratitude. My father was a diabetic and was rejected as a donor. My brother was much younger than me and was newly married. It pained me to subject him to such a challenging situation and I refused. The doctor declared my mother as a suitable donor; but I kept refusing. Could I live the rest of my life if something untoward happened to her while saving mine? My parents were worried sick and couldn't bear the thought of watching their daughter suffer. We were all internally torn.

The Much Needed Clarity: Wrought with anxiety and fear, I kept putting the decision off. My creatinine was closer to touching double digits and the nephrologist gave a strict warning that I might get into an emergency situation if I did not start dialysis immediately.

And then something miraculous happened, a much needed sign for our family. A couple, my parent's friends from my childhood days, came to visit us. We knew that, ten years back, Uncle had donated one of his kidneys to his daughter when hers had failed. It was amazing to see him that day – full of life, healthy and chirpy as ever. They shared that their daughter was doing quite well. This gave us confidence and a much needed clarity. Soon after that, we decided to go ahead.

In Feb 2010, while the compatibility tests were being conducted, my creatinine crossed 12. I could not escape dialysis. A catheter was inserted in my neck and dialysis was started. The first session was an extremely dreadful experience for me and I had to be hospitalised. I had to undergo 10 sessions of dialysis before the transplant date arrived. On March 19, 2010, my mother gave birth to me the second time. And I vowed to value and cherish this 'priceless gift of life' by taking good care of myself. It is now close to nine years since I received the kidney from my mother.

Gratitude: I am thankful that I can be there for my ageing parents and take them out for movies over weekends. I am thankful I am there for my 15 year old teenager as she faces the challenges of growing up. I am thankful to be able to go on vacations with my husband and daughter and to share a hearty laugh with them. I am thankful to be able to love and enjoy the work that I do. I am thankful and just happy to be alive.

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LUV STORY



Dr. Anirban Bose

DR. ANIRBAN BOSE

ANIRBAN IS THE Associate professor of Medicine and Nephrology at the University of Rochester in Upstate NY. Having experienced first-hand the problems patients in India face in their effort to get a kidney transplant, he has a long and abiding interest in renal transplantation from both a personal and professional standpoint.

Along with a group of likeminded people, he was instrumental in setting up MOHAN Foundation in the USA and seeks to further the cause of MOHAN Foundation. Anirban has authored 3 books titled, 'Bombay Rain, Bombay Gilrs', 'Mice in Men' and 'The Death of Mitali Dotto'

STORY

PLEASANTLY PLUMP with a gentle, bespectacled face, Luv Dhody is the kind of person one might have difficulty picking out from a lineup after having bumped into him only hours ago. Shy to the point of being aloof, he prefers not to be in the spotlight's glare. Perhaps, by western standards, his claim to fame –he received a liver transplant in India– is equally modest. And no, his story doesn't even make the headline-grabbing "organ-trafficking in the third-world" genre. Yet, in a country of a billion, absent a national system of organ recovery from deceased donors, the quirks of life, luck and love conspired against all odds to empower Luv's feat: he lives to tell his tale.

The first clue about the severity of his illness came in late 2002 when the gastroenterologist in Delhi sent Luv out of the room, breaking the news to his father instead that without a liver transplant Luv had less than six months to live. Liver transplants were feasible in the US or UK, but the astronomical price tag was far beyond the reach of a middle-class family like theirs. He suggested Luv quit work and live out his remaining days at home.

As a twenty-two year old fresh engineering graduate Luv was disturbed to overhear the conversation – not that he had less than six months to live, but that he should quit work at Tata Technologies where his employment had begun less than a year ago. Disregarding everyone's counsel Luv returned to his job, keeping his medical condition to himself, afraid his employers might let him go if they found out. He discounted his symptoms, blaming them on the food, the water or the environment, until one day blood began spurting from his nose so briskly that it bespattered his colleague's desk a few feet away. Then began the fainting spells where Luv would pass out at work without warning, panicking his co-workers and throwing the office into chaos. Alarmed, his managers joined the chorus of voices trying to convince Luv that it was in his best interest to hang up his hat and prepare for the inevitable. But Luv was adamant, pleading with them to let him continue, his natural reticence making it difficult for him to explain that his work was his refuge, his escape from his prognosis, allowing him carry on as if everything was

normal. Finally, when Luv's twin brother Kush, a doctor, proffered his services as a personal chaperone, willing to take charge of any emergent situation and absolving the company of any liability, Luv's bosses relented.

In the Hindu epic Ramayana, Luv and Kush are the twin sons of Lord Ram, born in exile after Sita, their mother, is banished to the forest by her husband. In contrast to the mythological twins who knew only their mother, Luv and Kush Dhody lost theirs to breast cancer when they were in their teens. Growing up with their grief-stricken father who had impoverished their generational family business trying to save his wife, the fraternal twins looked after each other and Kush stopped working after finishing medical school to stay with his brother round the clock.

Luv began to deteriorate, wasting away while his abdomen kept bloating with fluid accumulating in his belly. The fainting spells continued and to avoid panicking the office staff he'd curl up with a blanket in the air-conditioned server room whenever he felt ill. But he kept working, putting in longer hours, taking the company's late bus everyday. And it was during one of those rides that his eyes caught a small article tucked away in one corner of a newspaper announcing that King's College, London and Global Hospitals, Hyderabad were setting up a liver transplantation program in India.

When the surgeon from King's College declared that a liver transplant was indeed feasible in Hyderabad, Luv felt his expectations soar. But his bubble of denial burst, and, confronted with the possibility cheating death, he felt terrified of his diagnosis for the first time. Tempering his hopes, he and his family mulled over how best to deal with the many hurdles still left to overcome. Much testing had to be performed, a lot of money had to be raised, and, most importantly, a suitable organ from a brain-dead donor would have to be procured. That final, all-important task was left to a small private NGO called MOHAN foundation.

Since their founding in Chennai in 1997, Multi Organ Harvesting Aid Network or MOHAN foundation has been promoting deceased organ donation in India even as they battle headwinds of public misconceptions, infrastructural handicaps, governmental lethargy and funding hiccups. Their efforts have benefited thousands of patients, and their services have been recognized with prestigious honors such as the British Medical Journal's South Asia award in 2015. But their greatest success has been training hundreds of grief counselors – the foot soldiers who counsel the families of brain-dead patients. In a country where many myths and taboos about organ donation still prevail, it is a demanding, emotionally challenging job. But this is where rubber meets the road, and the entire program's success is dependent on the grief counselor's ability to comfort someone in their hour of greatest sorrow and still channel them to muster empathy for someone else's suffering: a fact not lost on Luv and his family when they met Global Hospital's grief counselor, Lalitha

“But their greatest success has been training hundreds of grief counselors – the foot soldiers who counsel the families of brain-dead patients. In a country where many myths and taboos about organ donation still prevail, it is a demanding, emotionally challenging job.”

Raghuram.

With her background in social work and the bona fides of having spearheaded the highly successful eye donation program in India, Lalitha was a natural fit to lead the Hyderabad office when MOHAN foundation began operations in the city in 2001. But she quickly realized that there was a world of difference between eye donation and organ retrieval. Being a woman amongst a bunch of older male doctors, holding her ground while discussing medical jargon without having a background in medicine and trying to change entrenched attitudes, practice patterns and outlooks took a lot of patience and persistence, honing these skills of hers into an art form. And those were the qualities the Dhody family witnessed as she counseled them, explaining the bounds of Indian law, the concept of brain death and why it was imperative for them to move to Hyderabad to have any shot at getting a liver. Most importantly, she reminded them that while her counsel and MOHAN foundation's services were free, nothing would move if they couldn't arrange for the hospital's charges for his surgery, hospitalization and anti-rejection medicines.

In India, financial constraints hang over a patient's head like the sword of Damocles, adding a dimension to the practice of medicine impossible to chronicle in a textbook of medicine. With little recourse from the law, sometimes profusely bleeding patients have been turned away from emergency rooms of private hospitals if they can't produce a minimum deposit that will make the doctor open a surgical sewing kit and stitch up a laceration.

Luv returned to work, uncertain how to proceed. When some of his office mates came to know, they hit on the idea of setting up a tax-deductible trust to pay for Luv's transplant, and a well-written letter from Lalitha helped them achieve their goal. As word spread around the office, the entire staff decided to donate a month's salary towards Luv's surgery. Once, in the middle of a high-level meeting with their company's head office, Luv suddenly fainted. Startled, one of the executives enquired about his condition, and, upon learning his diagnosis, started an email chain within the vast Tata Group of companies to raise money for Luv. The Dhody brothers began writing to different charitable organizations requesting support. His father began canvassing his friends and acquaintances in their hometown, Gwalior, making the most of his erstwhile business contacts to solicit funds. As money began to come in from different sources raising Luv's hopes and the feasibility of surgery, his managers let him move to Hyderabad, reassuring him that his job was safe and salaried for whatever time it would take him to get the liver transplant and return.

Having grown up in small town Gwalior, a big city like Hyderabad was a difficult adjustment for the Dhody brothers. Understanding a new language, learning new customs, navigating an unknown city and getting used to new foods imposed new hardships on Luv's health. For Kush, idle despite being a trained physician, it was particularly trying to watch his brother waste away while dealing with the unpredictability of when a liver would become available. He volunteered to donate part of his liver, only for Luv to turn him down because of the unacceptably high donor mortality rate of living donor liver surgery, still in its infancy in India.

And throughout this time, their one source of strength was Lalitha, the

person they'd go to almost daily to lighten the weight of the world on their shoulders. To her, the Dhody family's struggles mirrored her own hardships of a middle-class upbringing and so she indulged them uncomplainingly, providing them with updates and urging patience to keep their faith. Once, when Kush demanded to know why someone behind Luv on the waiting list had been given a liver, she patiently explained the size, age and sickness criteria behind that decision, and didn't take to heart that Kush left in a huff. Then, on January 15th, 2004, two days after Kush had walked out of Lalitha's office, Luv heard his phone ring. His hepatologist, Dr. Kapoor, was on the line, asking Luv to report to the hospital immediately for a liver transplant: a donor had finally been identified. Excited and nervous, Luv wondered fleetingly why the summons hadn't come from Lalitha.

Lalitha was busy. Swamy, her son, was home for the Pongal holidays, and together they were going to celebrate his nineteenth and his sister's fourteenth birthday on the 13th of January – a day both of them had come into the world albeit five years apart. On the morning of the 14th, Lalitha's mother called to let her know that her father wasn't well. Preparing to visit him in the hospital, she paid scant attention to her son's announcement that he was going to a farmhouse with his friends. Later that evening when she received another phone call from Swamy informing her that he would stay longer at the farmhouse, she updated him on his grandfather's condition and suggested he should perhaps return earlier to pay him a visit.

Early on the morning of the 15th Lalitha's phone rang and someone enquired if she could speak to Swaminathan's mother. Swamy had suffered a small accident and was admitted to the hospital. Could she come over soon?

Swamy lay on the hospital bed like someone enjoying a restful nap. There wasn't a single scratch on his body, not a drop of blood on his clothes. He looked calm, peaceful and content, except that he was unconscious, unresponsive to Lalitha's pleas for him to wake up. One of Swamy's friends filled Lalitha in on the details. On their way back to Hyderabad, Swamy, 6' 3" tall, had hit his head on the roof of the car when it veered off the road and overturned, the severe concussion causing his brain to swell uncontrollably. The medical fraternity of Hyderabad swept into action. All those doctors Lalitha had consulted, confronted, cajoled, convinced or counseled, rushed to offer the best medical care for Swamy. They moved him into intensive care, stabilized his vitals and consulted the best neurologists and neurosurgeons. But Lalitha was all too familiar with the scenario, having witnessed so many times in the past how death takes over despite a beating heart and a heaving chest. She knew what was coming: only this time her task to comfort and counsel a donor family was her own. Lalitha had explained brain death to many families previously and yet, for the first time, she understood what it meant. Her daughter cried inconsolably for a while and then agreed that they should donate all of Swamy's organs. Other friends and colleagues suggested they forgo donation if they weren't up to it: their track record in this field was ample proof of

“ And throughout this time, their one source of strength was Lalitha, the person they'd go to almost daily to lighten the weight of the world on their shoulders. ”



Ms. Lalitha Raghuram with her son
Swamy Narayan

their belief in this cause. Lalitha listened without paying attention. She felt disconnected, as though she was present but absent from the scene, and something or someone was guiding her actions that day, something bigger and better than she had ever seen or known, shepherding her to make the decisions that would impact four other lives. As Swami was moved to the operating room for organ retrieval, the only worry on Lalitha's mind was that the organ transplantation program was so new they wouldn't be able to find a recipient for Swamy's heart. In another operating room a few kilometers across town, Luv had been wheeled into surgery without any knowledge of his benefactor's identity. After eleven hours of surgery he woke up to hazy images of gowned and masked visitors walking into and out of his room. The waning anesthesia and scaling analgesia garbled their speech, adding to his confusion. But he heard a name, Mruthu, spoken over and over again, and hung on to it for its reassuring link to cognition even as he drifted in an out of awareness.

The foremost thought on Luv's mind as soon as his haze began to clear was not how well his new liver was working but what it would take for him to get out of the intensive care's "super-specialty room" posthaste to minimize the hospital's charges: a move predicated on his need for IV pain medication. Luv insisted they reduce the morphine, telling Dr. Kapoor that he was almost pain free even though he was hurting terribly inside. But at night, with little else to do, when the pain became unbearable, he lay writhing in bed hoping no one would notice.

His discomfort didn't escape the ICU nurse's watchful eyes, but instead of increasing his medication she came over and began talking to him. She knew what Luv was trying to do – like him she too was from a small town and had grown up with limited means – and so she talked to him throughout the night, distracting him from his discomfort until the first light of the morning when it was time for her to leave and Luv was too heavy-eyed to talk. When the next evening rolled around she was back, talking to him, forcing a conversation whenever he was awake and walking away if he fell asleep. They continued this routine daily, talking for long stretches at night, serendipitously discovering kinship and common ground while trying to cope with the oldest symptom in medicine. After about two weeks, when Dr. Kapoor pronounced Luv to be ready for the general surgical ward, Luv wasn't as thrilled as he thought he'd be. When Dr. Kapoor asked if he had any questions, Luv enquired awkwardly if he knew the night nurse's name. A surprised but dubious Dr. Kapoor nodded. Mruthula he said, but Mruthu to most.

Like Luv, Mruthula was a stranger in a strange city. Born and brought up in small town Kottayam, Kerala, she had moved to Hyderabad to study nursing and stayed on after graduating to work in the ICU of Global Hospitals. She didn't speak the local language, had few friends, and was working hard to save enough money. She took on extra shifts, her reputation for hard work and dedication earning her the distinction of being the ICU nurse for the most critically ill patients, including Luv.

After his discharge from the hospital, Luv had to stay in Hyderabad for a few months for his follow up care. He looked better everyday, gaining strength, eating more and getting his color back. His family was thrilled.

His reports were excellent: his new liver was functioning beautifully. And yet, Luv was restless, and only felt happy when, during one visit, a worried Dr. Kapoor informed him that they'd have to admit him to the hospital to treat early rejection. Could they admit him to the super-specialty room, Luv asked. Surprise on Dr. Kapoor's face quickly changed to annoyance. His misplaced priorities could cost him the liver, chastised Dr. Kapoor. How could Luv be so cavalier about of the seriousness of his condition? Didn't he know that a liver transplant isn't forever and, in India, has a shelf life of 5-7 years? Had he forgotten the waiting, the running around for money, the sacrifices his brother, his father, his co-workers and his friends had made? Had he forgotten that it had taken someone's death to give him this shot at life? Did he know the strange turn of events that had resulted in this donation... did he know the identity of his donor?

The paradox of organ transplantation is that the best organs come from the young, those who have died suddenly, unexpectedly, often traumatically, and to wish for life awaiting transplantation is to wish for someone else's untimely death. Tempered but tormented, Luv returned to work a few months later. Although his colleagues welcomed him back, their well-meaning curiosity made him re-live the events, among them his interactions with Lalitha. Soon Luv requested a transfer to their Mumbai branch, to a position that was much more demanding. He reasoned with his bosses who raised health concerns that he needed the higher pay the position offered because his anti-rejection medicines were running up a huge monthly tab. As was his cell phone bill trying to stay in touch with Mruthula.

Despite his remarkable turn around in physical health, talking to her was the one thing that made Luv feel better. He stayed long hours at work, taking on extra tasks, becoming very skilled at his job and very productive for his company, even though all he was trying to do was run out the clock till it struck 10pm when he knew someone would be beginning her shift in an ICU 500 miles away. She reciprocated his need for companionship, indulging him whenever time permitted, even changing her cell phone carrier to make the calls more affordable for him. Yet, despite their long tête-à-têtes spanning over two years, Luv was so afraid of his own mortality he could never get around to asking her if they had a future together.

In 2007, when Luv's bosses decided that he would be the ideal person to take on a major project in the US, Luv's father called him to Delhi for a big family get together. Luv knew this was an attempt to use the entire family's voice to pressurize him to entertain marriage proposals before he left for distant shores – proposals he had resisted thus far.

On his way to Delhi, Luv ran into Dr. Kapoor at the airport, and thanks to a weather delay, they were stuck in the terminal for a couple of hours. Following pleasantries, when Dr. Kapoor enquired lightheartedly if Luv was

“The paradox of organ transplantation is that the best organs come from the young, those who have died suddenly, unexpectedly, often traumatically, and to wish for life awaiting transplantation is to wish for someone else's untimely death.”

still in touch with Mruthula, Luv spilled the beans, confessing to him how torn he was about asking for her hand. When a nonplussed Dr. Kapoor failed to recognize Luv's dilemma, Luv reminded Dr. Kapoor that he had given the transplanted liver an expiration date of 5-7 years. Would he, Dr. Kapoor, agree to the marriage if Mruthula were his daughter? Dr. Kapoor fell silent for a while and then reminded Luv that we all have expiration dates, just not on our livers. For Luv's father, the Dhody family gathering was quickly getting out of hand. Amidst the tizzy of making arrangement for so many people and indulging their endless advice about Luv's marriage, Mr. Dhody nearly fainted when Luv dropped the news that he wanted to marry a south Indian nurse who didn't speak word of Hindi almost at the same time his youngest brother came out of the closet to declare to the family that he was gay. The senior Dhody traveled to Kottayam with hope in his heart and a proposal on his lips. Mruthula's parents were firmly opposed to the marriage, their objection solely on the basis of Luv's medical condition. Mruthula, the child of a mixed marriage (her father is Hindu and mother Christian), understood her parent's concern and agreed to not marry Luv, but also to not marry anyone else other than Luv. She also asked her parents to think long and hard what their answer would be had Luv asked for her hand and she, not he, was the recipient of a liver transplant.

An hour north of Chicago, in a quiet suburban neighborhood complete with tree-lined streets, manicured lawns and concrete sidewalks sit rows of modern looking condominiums. It is a far cry from the heat and dust and noise of Gwalior, Hyderabad or Mumbai, and, along with these, Luv has traded his Indian problems for American ones (job, commute, health insurance). He greets me warmly, escorts me inside and introduces me to Mruthula, who says a quick hello before disappearing and reappearing with piping hot tea and samosas. We talk over food and Luv shows me his photograph from when he had just graduated engineering college: a handsome young man smiling like someone without a care in the world. He tells me they sought Lalitha's blessings as soon as he and Mruthula finalized their wedding plans. I can hear a twinge of disappointment in his voice that despite his father's offer to send her airplane tickets, Lalitha couldn't make it to his marriage in Delhi. Having spoken to Lalitha about it I tell him that she didn't want to become a distraction during Luv's special occasion. Luv nods understandingly and is thrilled to learn that the Transplantation Society recently honored Lalitha with a "Women in Transplantation Heroes Award" at a glittering ceremony in Hong Kong. When I thank Luv for sharing his story he smiles and says how could he say no to Lalitha's request after she had said yes when it mattered most?

I spot toys on the floor, and almost on cue Mruthula comes down the stairs with five-year old Ira and eighteen-month old Ina. They are surprised to see me, but run to their father, curling up in his lap. He cuddles his daughters, rocking them back and forth, laughing when they squeal with delight. Then, without looking up at me he says, 'Life is such a miracle, no?'

OPPORTUNITIES FOR TRANSPLANT COORDINATORS

MOHAN Foundation has several rewarding learning and experience enhancing opportunities for all Transplant Coordinators

TRANSPLANT COORDINATORS' TRAINING PROGRAMME

Introduction

THE "TRANSPLANT COORDINATORS' Training Programme" is a pioneering initiative of MOHAN Foundation. A key factor for the success of an organ donation and transplant programme is a trained Transplant Coordinator and good coordination. The Transplantation of Human Organs and Tissues Act, (Amendment) 2011, made Transplant Coordinator nomination mandatory before a hospital was registered as a transplant centre. To address the training needs of this cadre of health care professionals, MOHAN Foundation started the "Transplant Coordinators' Training Programme" in 2009 – the first such structured courses in South Asia. The courses have been tailored to suit the requirement of candidates from varied educational backgrounds. The registration for these courses is subsidised due to part funding from the Tata Trusts, SBI Foundation and SBI DFHI Limited.

From December 2009 to October 2018 over 2000 candidates have been trained as Transplant Coordinators. MOHAN Foundation is partnering with the National Organ & Tissue Transplant Organisation (NOTTO), state government organ donation and transplantation organisations, hospitals and NGOs in conducting these training programmes.



(L to R) Dr. Sumana Navin, Dr. Suresh Badhan, Dr. Atul Mulay and Ms. Arati Gokhale handing over a completion certificate to Mr. Amol Netaji Dugaje from Wockhardt Hospitals, Nashik at the training held in Pune in 2018

Objective

Creating a cadre of health care professionals dedicated to “Transplant Coordination and Grief Counselling” in India and South Asia.



Participants and Faculty during the Ahmedabad training in 2012

Course Duration & Eligibility

- One-week training for Graduates in any subject, preferably with at least six months experience in a hospital.
- One-month training for Graduates who are freshers in this field.
- One-year Post Graduate Diploma in Transplant Coordination and Grief Counselling (online course) for working professionals who wish to add weightage to their qualification. This is a unique blended learning programme (E-learning with face-to-face sessions).

Curriculum

Learning is in four key areas - Organ and tissue donation, transplantation, grief counselling and transplant coordination - through lectures, presentations, activities, field visits, workshops, and projects.



Participants displaying their Posters on organ donation to (L to R) Dr. Sunil Shroff, Dr. Vimal Bhandari and Dr. Sonal Asthana

Faculty

The faculty members for the courses are from both medical and non-medical fields. The highly motivated and experienced faculty train, mentor and monitor the performance of the candidates undertaking the courses.

MASTERCLASSES IN ORGAN DONATION & TRANSPLANTATION

(Supported by SBI Foundation and SBI DFHI Limited)

A new initiative is a one-day masterclass, each focusing on a key topic, that enhances knowledge and endows Transplant Coordinators with practical skills to engage effectively in the workplace.

- ‘Make yourself heard’ - Soft skills and communication for organ donation and transplantation
- ‘The healing touch’ - Counselling and grief counselling for organ donation and transplantation
- ‘Leverage the power’ - Social media for organ donation and transplantation



Ms Pallavi Kumar moderating a role play on Family Counselling during the training held in Army Hospital Research and Referral in 2017

OPPORTUNITIES

Training Programmes and Masterclasses: The training programmes and masterclasses provide candidates with not only multiple opportunities to work in varied environments, but also expand their knowledge base and progress in their career paths.

Group photo taken during the FORT - Navjeevan-MFJCF Training Programme in Jaipur in 2017



Annual Transplant Coordinators' Conference and Advanced Transplant Coordinators' Workshop

Mentoring plays a very important role in increasing the effectiveness of trained Transplant Coordinators. MOHAN Foundation and the National Association for Transplant Coordinators (NATCO) organise an Annual Transplant Coordinators' Conference where Transplant Coordinators from across the country meet, interact, share challenges and success stories, and get a chance to update their knowledge. In addition, for senior Transplant Coordinators MOHAN Foundation holds an Advanced Transplant Coordinators' Workshop every year as well to enhance their skill sets and impart new learning. Many eminent national and international speakers share their experiences at these conferences and workshops.

Mini Fellowship in Organ Donation, Philadelphia, USA

Senior Transplant Coordinators with a minimum of three years' experience are eligible for a two-week Mini Fellowship in Organ Donation at Gift of Life Institute, Gift of Life Donor Program, and Albert Einstein Medical Center, Philadelphia, USA worth US \$ 4,000. The Mini Fellowship is supported through an educational grant from MOHAN, USA.

— **DR. SUMANA NAVIN & ANN ALEX**
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SWAMY NARAYAN BEST TRANSPLANT COORDINATOR AWARD

ABOUT THE AWARD

SWAMY NARAYAN was the son of Lalitha Raghuram, Country Director of MOHAN Foundation. Both she and her husband Raghuram have championed the cause of organ donation since 2001.

Following a tragic road accident on 13th January 2004, Swamy was declared brain dead. While Raghuram and Lalitha were already working for the cause of organ donation, this accident came as a bolt out of the blue. However, the couple demonstrated exemplary courage and conviction by donating Swamy's organs, thereby giving a new lease of life to five patients.

In 2009, CNN IBN recognised their selfless service and honoured them with the CNN IBN's "Real Heroes" Award, wherein they received a trophy and a cash award of INR 5 Lakhs. They donated the amount to MOHAN Foundation from which an endowment has been created to recognise the Best Transplant Coordinator each year.

This was the genesis for the "Swamy Narayan Best Transplant Coordinator Award". Several Transplant Coordinators from across the country have received the award since 2010.

2010, **Niveditha Sankaran**
Service Line Manager
Southern Region (Former)
Apollo Hospitals Chennai



2013, **Ms. Bhavana Shah**
Executive Administration Wock-
hardt Hospital, Mumbai



2012, **Mr J Nethaji**
Programme Manager Organ
Transplantation
Global Hospitals, Chennai

2014, **Mr Senthil Kumar S**
Transplant Coordinator, Govt.
Stanley Medical College &
Hospital, Chennai



2012, **Ms. D Keranal**
Transplant Coordinator, Apollo
Hospitals, Chennai



2013 Special Recognition, **Mr Sagayam Francis**
Executive Officer - Transplantation
MIOT International, Chennai



2013, **Ms. Sarala Anantharaj A**
Deputy General Manager
BGS Global Hospital Bengaluru

2014, **Dr. Muneet Kaur Sahi**
Programme Manager, MO-
HAN Foundation, NCR





2016, **Ms. Surekha Shantanu Joshi**
Manager MSW Department &
Senior Transplant Coordinator, Grant
Medical Foundation,
Ruby Hall Clinic, Pune



2015, **Mr. Jacob Mathew**
Senior Manager, Administration
Lakeshore Hospital, Kochi



2018, **Lt Col Sandhya V Nair**
Senior Transplant Coordinator
Army Hospital Research &
Referral, Delhi



2015, **Major Joyot Chattopadhyay**
Administration Officer, Indian Army



2017, **Mr. Shankar Ganesh**
Senior Transplant Coordinator
Gleneagles Hospitals, Chennai



2016, **Mr. Navdeep Bansal**
Organ Transplant Coordinator
PGIMER, Chandigarh



2018, **Mr. Bhanu Prakash**
Transplant Coordinator
MOHAN Foundation, Hyderabad

LIFE BEFORE ASHES

"LIFE BEFORE ASHES" is a unique art installation by MOHAN Foundation to raise awareness on organ donation. It exhibits re-creations of human organs with ashes of the deceased and mud, to convey the hard hitting message that what has now become ashes, could have been another person's heart or kidney, if only the organs had been donated.

It also conveys that while people are ready to allow their loved ones' organs to be burnt and wasted along with the body, they are not willing to let the organs give a new lease of life to someone who is in dire need of it.

The ashes used to re-create the organs were collected after the cremation of a Mumbai based senior citizen whose family agreed to part with the last remains for the cause of raising awareness on organ donation. The mud used to bind the organ replicas was also collected from the crematorium ground.

This is a moving exhibition and is currently available in Delhi, Mumbai, Chennai, Jaipur and Hyderabad. If you are interested in exhibiting this art-work installation at your hospital, kindly contact MOHAN Foundation.



THE BIRTH OF A FOUNDATION



Dr. Sunil Shroff
Founder & Managing Trustee

Dr. Sunil Shroff is a leading urologist, transplant surgeon and a social entrepreneur who has been instrumental in establishing the deceased donation and transplantation program in India. He was one of the first to publish his experience with the application of the holmium laser in urology from the Institute of Urology, London UK in collaboration with his mentor Dr. Graham Watson.

He is currently the Senior Consultant Urologist at Madras Medical Mission Hospital. He performed the first kidney transplant on an HIV positive patient in India and transplant of kidneys from cobra-bitten brain death victims. As a founder trustee of MOHAN Foundation, he has been actively promoting the concept of deceased donation after brain death since 1997. Through the Foundation, he has worked for policy improvements and amendment of the law to ease deceased donation in India. He has campaigned against organ commerce and believes that such activities which are reported widely by the media adversely affect public perception and acceptance of the deceased donation programme.

"I know of no higher fortitude than stubbornness in the face of overwhelming odds." - Lois Nazer

The year 1995 was to be the year of hope and a new change for the organ donation program in India. The transplant law had just come into force in the month of May. This had come about after few years of discussion and deliberations and some pressure from international bodies to stop organ trade. The law enlarged the scope of the program by recognising brain death and gave hope to patients, not only with kidney failure but also to patients who required heart, liver, lungs and other solid organ transplants.

Coincidentally, in the second week of April the same year, I relocated to India after having spent over a decade in the UK. I had worked in the transplant program for a few years and had taken many organ retrieval calls and over the years developed a fair grasp of the clinical requirements to implement the deceased donor program in a hospital. The flurry of activities during deceased organ donation, the phenomenal team work, the family's willingness to help others at a time of extreme grief and the life-saving organ transplants that followed to multiple patients, gave the program a unique medical and societal importance. The lives saved from lives that were often lost in tragic circumstance gave such transplants a human perspective that was so different from other surgeries in medical science.

The hours in the program were long and sometimes very tiring but the gratification it provided to us working professionals was immense and the life-force it created within the ecosystem was unmeasurable. The unparalleled nobility of such donations was a stark contrast to the murky organ trade that was happening in India. To me, it was this 'contrast' that triggered the desire to make a change, to make a difference. A difference that had the power not only to cleanse our program in India but also had the power to save multiple lives.

The general belief in the minds of the clinicians at that time was, 'no one will say yes to organ donation in India.' However, I found people were saying yes to eye donation and this belief was reaffirmed by a large survey on organ donation. So, I said to my friends in the Intensive care, "Why don't you ask for eyes first and see the reaction of the relatives? If they said yes to eyes, maybe they could ask for other organs." The penny seemed to have dropped at this simple idea and a conversation about organ donation in futile cases such as brain death started in my ICU and soon enough we started doing a few donations and the eye donation numbers in the hospital increased almost dramatically.

Over a year had passed after the transplant law was passed but only

a handful of donations were happening in a few hospitals in the country. The program seemed to be a non-starter, hope was fading fast, the obstacles to kick start the program in a hospital seemed to be unsurmountable and the race seemed to be lost even before it had begun. The thought leaders in the program became the detractors and they vehemently opposed the program. They felt that the acceptability of brain death concept by the public was going to be impossible in our multi-cultural, multi-religious, economically challenged and diverse society. However, in my own hospital, I sensed that the reluctance was coming more from our own doctor colleagues and not so much from the public at large. The ICU staff would just disconnect the ventilator in a futile case without even so much giving the possibility of organ donation a thought. There were no mechanisms to identify, certify or maintain brain death. The few donations that were happening required constant push from a few committed staff. There was no family support to help with the decision to donate in their difficult hour. The concept of counsellors and coordinators was alien and even in my own hospital the appointment of such a staff in the year 1995-96 proved to be a topic of debate.

Having struggled for over 18 months, the idea that germinated was to create an organisation to fulfil the needs of this struggling program. An organisation that could work like a support system for the public, physicians and the patients.

At the 12th annual conference of the 'The Indian Society of Organ Transplantation' (ISOT) in Chennai from January 9 – 12, 1997, we decided to launch this organisation. On the last day we invited the public so as to gather support for organ donation and at the same time honour the few organ donor families and inspire the public by planting a few saplings in the memory of the donors in our beautiful campus of Sri Ramachandra Medical College. It was during this function on January 12, 1997 MOHAN Foundation was born. Actress Revathi Menon received the first donor card along with many other celebrities.

The first two years were spent on conducting umpteen number of public education programs. The response would be mixed, we would often distribute our pamphlets and in the end when the crowd dispersed, pick some of the untouched ones and pack them to be ready for another awareness program.

The change in our purpose came in October 1999, when we honoured the organ donor families in a public institution in Chennai. It was during this function that we realised that we needed to do more than mere public education to uplift the program. What was required was a proper organ sharing and allocation system for optimal utilisation of organs and to evolve a mechanism that would make the program more ethical and transparent.

Soon after this function, a meeting of four key hospitals in Tamil Nadu that were regularly doing deceased donation was called and everyone present agreed that an organ sharing system based on few simple prin-

“I know of no higher fortitude than stubbornness in the face of overwhelming odds.” - Lois Nazer

ciples was required. The first of such principle was 'no organ should be wasted.' The second was to keep one kidney in the hospital that was doing the donation and the second to be shared in the common pool waiting list. Heart, lungs and liver were to be shared by rotation unless an urgent alert was raised. The plan was to run a one year pilot program and reassess the system. The group was to meet once a month and share their learnings and make plans on how to make progress.

There was no looking back after that. Over the next nine years, the monthly meetings provided not only leanings but strengthened the group bonding and gave them a sense of purpose and accomplishment. Most importantly, it provided a model that could be replicated by others. In 2002, we began work in Andhra Pradesh happened – a state that had no donations at all. The learnings from Tamil Nadu ensured that regular donations from almost all major hospitals in the state started happening.

All the work and the small successes gave belief that this less traversed path could yield the desired results. This resulted in paving a way forward for the government of Tamil Nadu and Andhra Pradesh to set systems in place and centralise the program through creation of a nodal body in the state. In 2012 and in 2014, two other states Kerala and Rajasthan came forward and expressed a desire to start the program on the lines of Tamil Nadu and signed a MoU with the Foundation for three years to chalk out the required road map. The principles of organ sharing have remained

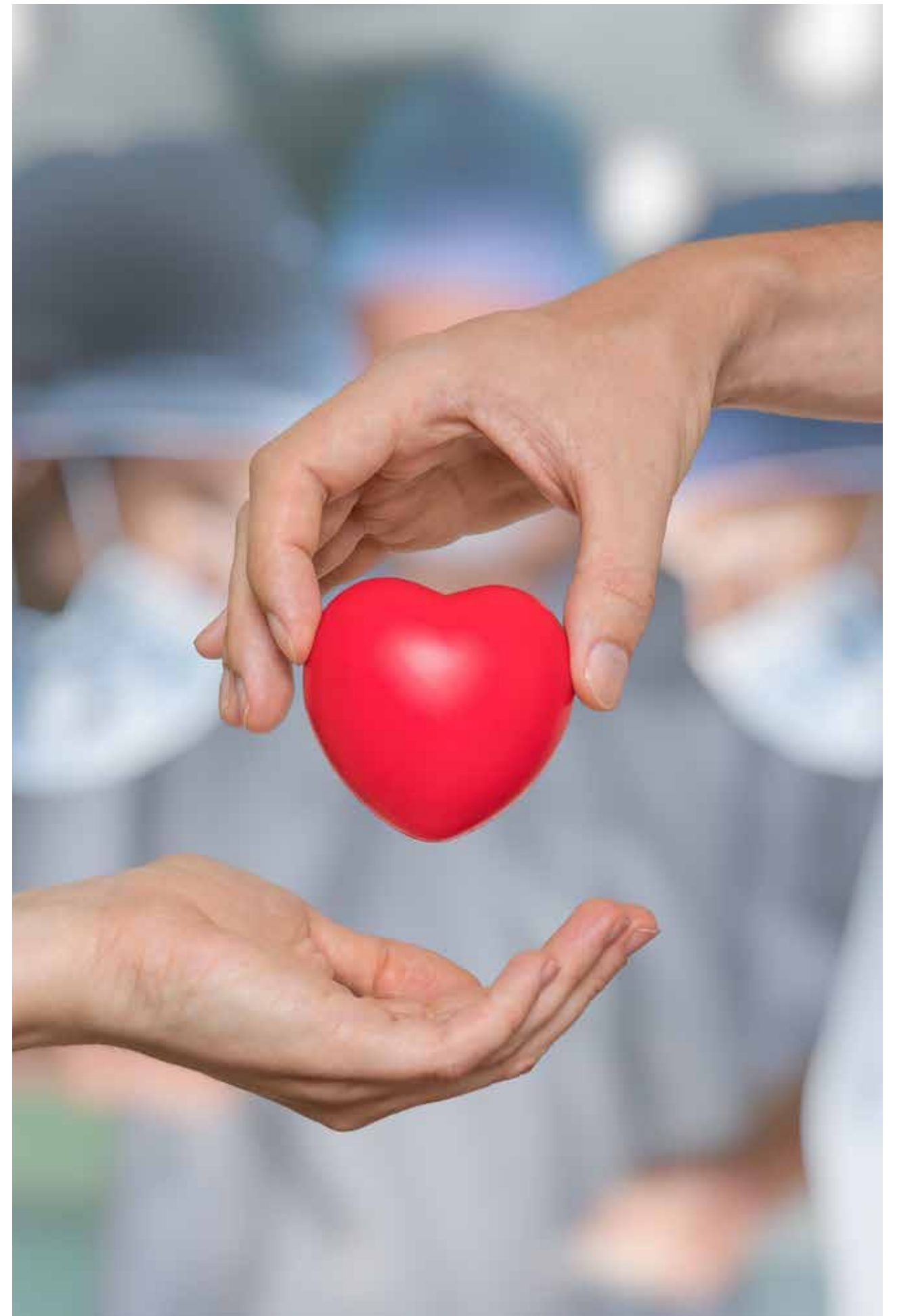
the same in some of these states and have not changed much since their very inception in 1999.

The Foundation has grown over the years, expanding its presence in India and outside of it. It remains committed to its vision of ensuring that every Indian that is suffering from end stage organ failure be given a second chance in life to receive the gift of a new lease of quality life through a lifesaving organ.

— **DR. SUNIL SHROFF**
Founder & Managing Trustee

"No matter what people tell you words and ideas can change the world." Robin Williams

“*No matter what people tell you words and ideas can change the world.*”



ABOUT MOHAN FOUNDATION

MOHAN (Multi Organ Harvesting Aid Network) Foundation is one of the leading NGOs working in the area of Organ Donation in India and has been a pioneer in many ways. Started in 1997 in Chennai, it started advocating this very difficult cause at a time when no one in the country was talking about it and the environment was fairly hostile towards this highly taboo topic.

Its unique mission is to ensure that every Indian that is suffering from end stage organ failure, be given a second chance in life to receive the gift of a new lease of quality life through a lifesaving organ.

India's estimated donation rate is at a mere 0.80 per million population which is not enough to meet the current organ needs in our country. India is struggling with an acute shortage of organs increasing the agony of those awaiting a lifesaving organ transplant. Many people die waiting for an organ. MOHAN Foundation was established to address this challenge. The Organization facilitates this with the help of a group of extensively trained and passionate staff who creates awareness, work closely with hospitals, train medical professionals and effectively counsel families in hospitals to encourage them to think about organ donation and save other lives in their moment of grief and loss.

The organization's activities cater to a specific set of objectives:

- **Initiating Public Education Programs to promote Awareness**
- There is very little public awareness around organ donation. In the absence of fact based knowledge and understanding, people harbor many myths and misconceptions. The Foundation regularly conducts public awareness programs for all sections of the society including schools, colleges, clubs, corporates and medical professionals. These programs not only help bridge the gaps in knowledge, they also help people to make an informed decision to pledge for organ donation in the form of Donor Cards. MOHAN Foundation has sensitized over 20 million people about organ donation.
- **Networking with Hospitals to enable Donations to occur** - The Foundation works closely with hospitals across the country to help lay down Standard Operating Procedures and guidelines for successfully carrying out a Deceased Organ Donation and Transplantation Programme within the hospital. The foundation has initiated the 'Oxford Organ Retrieval workshop' of the UK to train surgeons into the best practices for organ retrieval and organ implantation. These workshops have trained 170 surgeons over the last 5 years.



MoU between NHSBT and MOHAN Foundation being signed at the House of Lords, UK

The Foundation has also developed a highly interactive curriculum for ICU consultants and staff on brain death identification, management and certification.

A Phone App has been developed for Donor Optimization for ICU staff in association with NHSBT (National Health Service Blood & Transplant) of the UK.

- **Training Transplant Coordinators in counseling families of the deceased for enabling more donations** - The organization has been training a special cadre of professionals called Transplant Coordinators who do the unenviable job of counseling bereaved families to support them in their decision to donate the organs of their deceased loved one and save other lives. Speaking to families who have just lost a dear one is no easy task and needs to be done with sensitivity which the coordinators are trained for in addition to coordinating the entire process of donation and transplant in a timely and effective manner. Over the past nine years, the Foundation has trained 2138 (over 2,100) Transplant Coordinators through 60 training programmes (52 workshops) of one week, one month, six months and one year.
The online e-learning course for Transplant coordinators (el.mohan-foundation.org) attracts not only Indian but also international students.
These trained Transplant Coordinators are placed in hospitals where they sensitize the para medical staff, conduct activities both within and outside the hospital to generate awareness and coordinate the entire process of donation if the family consents.
- **Liaising with Government bodies to pass favorable legislations that augment organ donation** - The Foundations' ongoing efforts have been to liaise with Government at the Centre and at the State level. It has been a catalyst in making a few amendments to the existing Transplantation of Human Organs Act, 1994. The Foundation is on the advisory committees initiated by Government of Tamil Nadu, Andhra Pradesh and Rajasthan.

Ms. Lalita Raghuram receiving the BMJ Award for Health Care Advocacy



- **Capacity building of SAARC countries** - MOHAN Foundation has conducted training programs in Bangladesh, Nepal, Sri Lanka and Pakistan on deceased organ donation. The Foundation has helped Pakistan and Bangladesh with their legislation on organ donation and brain death.

Awards and accolades - MOHAN Foundation for its continuous and ongoing efforts to boost the organ donation rate of India has been recognized on various platforms. A few prestigious recognitions include -

1. The British Medical Journal South Asia Award 2015 in the Health-care Advocacy category for its relentless efforts to promote organ donation in India and South Asia for the past two decades.
2. Rashtriya Swayamsiddh Award in the category (Health) by the JSPL (Jindal Steel & Power limited) Foundation.
3. PoleStar Social Impact Awards 2017 for the Health category – Health
4. One of three finalists at British Medical Journal Awards South Asia 2018 in Excellence in Medical Education category – for the ‘Transplant Coordinators’ Training Programme’

Major Publications- The Foundation has done some major research oriented work and has got articles, books and newsletters published in its name.

1. The Foundation has been publishing the ITN (Indian Transplant Newsletter – <https://www.itnnews.co.in>) every quarter for the last 20 years – a hard copy of the newsletter reaches out to over 2000 doctors and paramedical staff across the country.
2. The Foundation has published books on “Legal aspects and organ donation” and on “Religion and organ donation”
3. The Foundation regularly contributes articles about the Indian deceased donation program in various Indian and international Journals.



Release of the first donor card in Chennai in 1997

Since its inception the Foundation has grown and spread its reach by setting up offices in many other parts of the country like Hyderabad, Delhi-NCR, Mumbai, Jaipur, Bangalore, Nagpur, Chandigarh and Imphal. It even has a presence in USA.

All the services rendered by MOHAN Foundation are free. It is guided by the ethical and legal principles of Transplantation of Human Organs Act of 1994. The Foundation survives on the philanthropy of the community.

All these efforts has helped in India’s deceased donation rate going up to 4 times in five years (196 organ donors in 2012 to 830 donors in 2016 that resulted in 2200 solid organs).

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