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INTERNATIONAL CONFERENCE OF TRANSPLANT COORDINATORS &
8th National Bioethics Conference of Forum for Medical Ethics Society

21st & 22nd November 2020

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We acknowledge the inputs of the scientific committee members for developing the deliberations during the sessions. We thank the speakers and the chairpersons for sharing their thoughts and experiences during the meeting.

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Mrs. Lalitha Raghuram
President
NATCO

7 January 2020
Contents

21st November, Day 1 Proceedings

Session 1: The World Brain Death Project

Introduction to the Project .......................................................... 1
Dr. Kandamaran Krishnamurthy

Application in India .................................................................. 3
Dr. Kapil Zirpe

Session 2: Communication from Behind the Mask – Medical and Donation Conversations

The ICU Doctor’s View ................................................................. 9
Dr. Ben Ivory

The Specialist Nurse’s View ......................................................... 9
Ms. Jill Featherstone

Session 3: Are we ready for Transplant Pregnancy Registries? ....... 9
Dr. Nithya Krishnan

Session 4: Mini research projects for members to strengthen NATCO 25
Dr. Sunil Shroff

Inaugural Ceremony .................................................................. 44
22nd November, Day 2 Proceedings

Session 1: Confusion over coordination – an Ethical view of organ allocation

Mrs. Arati Gokhale
Ms. Trilly Rachel Mathew
Dr. Amit Joshi

Session 2: Donation protocol during COVID-19

USA

Ms. Susan Gunderson

India

Dr. Manisha Sahay

Session 3: A Walk in My Shoes: Transplant Coordinator’s Recovery Story after COVID-19 Infection

Mr. Ciju Nair
Mr. Ahsan Ansari

Session 4: Increasing the Donor Pool during the Pandemic

Mrs. Arati Gokhale

Session 5: Patient Support during COVID Pandemic

TC driven approach

Dr. Sujata Rajapurkar

Group driven approach

Ms. Jaya Jairam

For underprivileged patients

Mr. C.Y. Pal
Session 6: Indications for Lung Transplantation with special reference to COVID Infection

Dr. Sandeep Attawar

Session 7: Women in Transplantation – Some Memorable Journeys

Dr. Nancy Ascher
Dr. Lori West
Dr. Vasanthi Ramesh
Mrs. Lalitha Raghuram

Session 8: My First Deceased Donation or Unique Transplantation – from a young TC

Lt. Col. Anita Nair
Dr. Nagraj Naik
Mr. Amit Chauhan

Session 9: Reinventing Ourselves in the New Normal

Mr. Rajeev Maikhuri, ORBO
Ms. Sunayana Singh, ORGAN India
Mr. Nilesh Mandlewala, Donate Life
Mr. Rajesh Shetty, Rebirth
Mr. Anil Srivatsa, Gift of Life Adventure
Dr. Kulwant Gaur, Shine India
Ms. Pallavi Kumar, MOHAN Foundation
Ms. Sreelakshmi Satyan, Quit to Care

Session 10: Panel discussion – How to Start a New Skin Bank in your Hospital?

Dr. Somesh Balakrishnan
Dr. Rajesh Powar

Vote of Thanks

NATCO Committee

List of Faculty

NATCO Membership Form
Day 1 – 21st November 2020

Welcome Address: Mrs. Lalitha Raghuram – President, Network and Alliance of Transplant Coordinators (NATCO)

Mrs. Lalitha Raghuram welcomed the faculty, speakers and members of NATCO to the International Conference of Transplant Coordinators, 2020. The virtual conference featured international faculty from the US and UK and was attended by participants from Nepal, Pakistan, Bangladesh, Sri Lanka and all over India. The focus of the conference was on the new protocols for brain death declaration, protocols for donation during COVID and women in transplantation among other topics.

Session 1: World Brain Death Project

Chairpersons: Dr. Ganapathy K and Dr. Deiveegan K

Dr. Ganapathy kicked off the session by revisiting the first brain stem death declaration that was done and organ donation that followed it in 1995 in India. This was India’s and South Asia’s first multiple organ cadaveric transplant. Without any precedence and in the absence of transplant coordinators it was a totally different story. A heart, kidneys and liver were successfully transplanted on Christmas day 1995. From there on he has certified more than 100 brain stem deaths between 1995 and 2003 and actively created awareness of brain death whenever and wherever possible.

In his paper Brain Death Revisited, published 3 years ago in Neurology India, he had concluded that there is a lack of international consensus on what legally constitutes brain death. This has been the case even quarter of a century later since the concept of brain death was first introduced. In the Indian context, Kerala has been the only state so far that allows brain death to be entered in the medical records. It has been a practice to put down cardiac arrest, which actually is only a mechanism and not a causal factor for death. Kerala has allowed its doctors to certify BSD even in scenarios where organ donation is not being considered. It is recommended the other states also follow this practice.

Two years ago a Supreme Court judges in a five bench legalized advanced medical directives and formalized the living will which the Western countries did 40 years ago.
Dr. Deiveegan mentioned it has been a great journey for him personally, in the government sector in terms of brain death declaration. The first certification was done in 1997 in Madras Medical College. The appointment of transplant coordinators in all government medical colleges, thanks to the efforts of MOHAN Foundation has been a boost to the programme. Mr. PWC Davidar, the then Additional Health Secretary, made sure that all the government medical colleges had Neurologists and Neurosurgeons appointed to make BSD certification possible, paving way for great progress. However, down the years probably the enthusiasm to certify BDs has come down and government institutions are performing poorly as compared to earlier days. Dr. Deiveegan strongly believes that the programme will bounce back and there will be great progress.

**Introduction to the Project**

**Speaker: Dr. Kandamaran Krishnamurthy**

With the advancements in organ support facilities, it is becoming increasingly difficult to certify brain deaths. The neurologists, neurosurgeons and other critical care team members all over the world are attempting to determine brain death or death by neurological criteria. The diagnosis practices hugely vary between countries and even within the different regions of a country. This was explained with the example of the Jahi McMath case where religious beliefs of the family did not permit them to accept the BD certification and refused withdrawal of life support.

The World Brain Death Project (WBDP) brought together international professional societies and other contributors including critical care, neurology and neurosurgery in an attempt to arrive at a consensus and develop gold standard criteria for diagnosing brain death. WBDP undertook extensive literature searches between 1992 and 2020 to achieve this. The group proposed that BD/DNC, which should be a clinical determination, could be defined as “the complete and permanent loss of brain function as defined by an unresponsive coma with loss of capacity for consciousness, brainstem reflexes, and the ability to breathe independently.” (Greer, Shemie, et al. JAMA 2020)

**Historical Aspects of Brain Death:** It began with the argument if brain death was equivalent to human death and the concept of death of an organism as a whole versus the technology enabled functioning of certain organs. Until the 1950s cardiopulmonary criteria was used to determine death before CPR and PPV came into being, paving the way for the BD concept.
Beginning with the Harvard Committee in 1968, Minnesota Criteria in 1971, the UK guidelines in 1976 and the UDDA in 1981 have all been attempts at arriving at consensus for defining death in various situations moving beyond just cardiopulmonary death.

The WBDP has published an all-encompassing article in JAMA, followed by 17 supplements, aiming to address the various issues around BD/DNC certification and establish a gold standard. This can be used as the go to guideline even by institutions that may lack infrastructure to do the certification. It also offers great scope for further research in this area.

However, there are groups that still contend the concept of brain death – terming it as legal fiction to merely permit organ donation; citing the possibility of physiologically maintaining brain dead persons for even years; and refusal to accept on religious grounds.

**Whole Brain Death and Brainstem Death:** While there may be anatomical variations between the two, the clinical examination is the same for both; uniformity in terminologies can make things easier. Countries should be guided by the laws in their jurisdiction. In regions that equate whole brain death to BD/DNC, the diagnosis should not be done until the blood flow stops in the supratentorial and infratentorial regions of the brain; ancillary tests should be performed as appropriate.

The WBDP document offers a six-step flow chart to guide the BD certification process right from identifying a potential irreversible brain injury until up to declaration and documenting the BD/DNC. **The specific minimum criteria for determining brain death are – absence of consciousness, brainstem reflexes and apnea.** The clinical exam components that are recommended, include absence of awareness/arousal, facial movements, gag and cough reflexes, corneal, oculocephalic, and oculosvestibular reflexes dilated pupils, among others. The paramedics, nursing staff and other intensive care team members should be made aware of the possible spine reflexes and other movements that could be observed in brain death diagnosis; the family of the patient should also be explained this.

In the presence of confounding factors it is recommended that ancillary tests be performed. Special consideration may be required if the patient is:

- a child
- is receiving ECMO support
- is receiving therapeutic hypothermia
The following must also be taken into account:

- Religious, societal, and cultural perspectives
- Legal requirements
- Resource availability

It is important to look out for brain death mimicking conditions - leptomeningeal carcinomatosis, snake bites, high cervical spinal cord injury, electrolyte imbalance and rabies, among others may mimic BD diagnosis.

Step by step guidelines for determining BD/DNC in patients treated with therapeutic hypothermia starting from rewarming, obtaining neuroimaging up to performing clinical exams and apnea has also been recommended by the WBDP. Checking for levels of drugs including various opioids and sedatives to rule out confounding factors like pharmacologic paralysis is also listed. The project also recommends when to perform ancillary tests and the lists of tests that have to be performed; conventional 4-vessel cerebral angiography/DSA, radionuclide study, transcranial Doppler and EEG alongside SSEP and BAER are a few recommended. A comprehensive checklist on ancillary testing (reasons to perform and list of tests) for determining BD/DNC in adults and children (≥36 weeks of age) is also available; in many instances it might be difficult to perform these tests owing to lack of infrastructure.

For both adults and children on Extracorporeal Support – ECMO, the fundamentals applied would be the same; specific guidelines for carrying out the apnea are provided by the WBDP document. Ancillary tests are to be performed in cases where apnea cannot be safely done.

The WBDP has laid out criteria and qualification of professionals who can determine BD/DNC, bearing in mind that highly qualified professionals may not be available always and everywhere. It also recommends that students in all healthcare fields are educated about BD/DNC and trained in counseling families. Certification courses are also available.

The regional legislation should be applied to declare the time of death. However, in the absence of such legislations, the second test should be considered as the time of death. The hospital staff should be aware of the local religious and cultural beliefs and trained to appropriately communicate with families.

Dr. Krishnamurthy then talked about his paper ‘Brain Death – Moving beyond Consistency in the Diagnostic Criteria,’ that he has coauthored with Dr. Truog and Dr. Tasker, which focuses on the
ancillary tests, particularly in pediatrics field. Inconsistencies continue to remain in pediatric BD/DNC determination around the world.

Within Asia there are variations in brain death determination, in terms of whole brain versus brainstem concept, number of professionals required to certify, PaCO2 threshold levels, requirement of ancillary tests, etc.

Application in India

Speaker: Dr. Kapil Zirpe

Dr. Zirpe, as a member of the WBDP writing and review committee, has contributed Indian perspectives to the project which has addressed many concerns in BD determination faced by the country.

The THOA since its inception has undergone amendments and it is now the time for medical professionals, non-governmental organizations and others engaged in the field of organ donation to arrive at a consensus about what changes have to be made in the law to improve organ donation rates in the country and present it to the government. The WBDP guidelines will act as a reference for this.

The WBDP reference document must be made available in every hospital and discussions around this should be initiated everywhere to arrive at a consensus. As of 2017, Asia had an organ donation rate of 1.1pmp whereas in the US it was 20.7pmp. Though there has been an improvement in the donation rates of India between 2010 and 2018, it has not been a consistent rise. The major concerns in the Indian context include:

- Inconsistencies in criteria and practice of brain death
- Poor concept of potential donor
- Lack of extended criteria for declaration – moving beyond just RTAs; avoiding losing unstable donors
- Variable clinical practices
- Poor understanding of laws – inconsistent interpretation of the law
- Weak legal system – doctors are not well protected
How the WBDP address these concerns:

- It recommends a standard definition for brain death and suggests that use of brain death/death by neurologic criteria (BD/DNC) terminologies to achieve uniformity
- Considering BD/DNC as a clinical determination, regardless of the possibility of organ donation and performing all neurological assessments for BD certification. This will ensure availability of quality organs and prevent crashing of donors in the ICU
- Offers precise guidelines to perform the apnea and suggests ancillary tests for scenarios where apnea cannot be performed
- It has been suggested that a single exam, including apnea testing, is adequate in determining BD/DNC in adults; the time presently spent between the two set of tests could be saved and possible donor crashes during this time could be averted
- Recommends that ancillary tests should not be used for the diagnosis of BD itself; these tests may be used to help families understand the clinical determination better if there is resistance or uncertainty
- Recommends an adequate observation period prior to the clinical testing for BD/DNC
- Determination of brain death/death by neurologic criteria in patients on ECMO reviews ECMO principles, gas exchange physiology and provides guidance for apnea testing in patients on ECMO
- Determination of brain death/death by neurologic criteria after treatment with targeted temperature management (TTM) provides recommendations and suggestions to avoid erroneous determinations of brain death in those who have been treated with TTM
- Defines the educational and professional qualifications and experience requirements of those who can determine BD/DNC
- It suggests that the law and other orders indicate that:
  - there should be no need for consent for performance of the clinical evaluation, apnea testing or ancillary testing for determination of BD/DNC
  - families declining to accept the BD/DNC determination on any grounds could be refused further advanced treatment, including cardiopulmonary resuscitation
- discontinuation of somatic support to be allowed, despite request from family, if the bed is required for a living patient (suggested guidelines by WBDP)
- all hospitals adhere to the most up-to-date national guidelines

Dr. Zirpe also highlighted the vast variations in brain death determination in Asia and how the WBDP project aims to overcome this and achieve international harmonization to minimize errors and enhance the deceased donation programme. It can be adopted in the existing legal framework by all countries. The WBDP document will serve a large multidisciplinary group of healthcare professionals to help develop new protocols and resolve disputes.

Comments/Questions

Q: Why is somatic support offered only for 48 hours?

A: 48 hours is a reasonable time for the family to come to terms with the diagnosis and consider taking second opinion for their satisfaction. It is easier if the patient is an older individual and special consideration will be required for pediatric patients.

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Session 2: Communication from Behind the Mask – Medical and Donation Conversations

Chairpersons: Dr. Sunil Shroff and Mr. Howard Nathan

Views of an ICU Doctor and a Specialist Nurse

Speakers: Dr. Ben Ivory and Ms. Jill Featherstone

The COVID-19 pandemic and the resulting lockdown have been affecting the lives of millions across the world, but the healthcare sector is at the epicenter of this unprecedented global pandemic challenge and the private sector has risen to the occasion by offering the Government all the support it needs, be it testing support, preparing isolation beds for the treatment of COVID-19 positive patients or deploying medical equipment and staff in identified nodal hospitals. General practices within the hospitals in UK have been modified to manage patients with chronic conditions and patients who need critical care. From mid-March 2020, the way general practice works, has profoundly changed. All the practices have been moved to remote triage, where patients are assessed over phone or virtually before they can access a General
Practitioner or other health professionals. The hospitals have started exploring chat process and video calls to connect and to spend time with the family members of the patients.

Dr. Ben Ivory started his presentation by mentioning that the year 2020 has been a unique year for healthcare sector and has presented a lot of challenges in the systems. Dr. Ben and Ms. Jill Featherstone shared their experience in communicating with the staff, patients and the family members during COVID times. Some of the major points that they raised from their PowerPoint presentations are:

The challenges of COVID-19 – communication between hospital staff, patients and families:

- One of the most pressing of challenges during the COVID-19 pandemic is the requirement for hospital staff to wear enhanced PPE (Personal Protective Equipment) in all operating rooms, to protect staff against droplet and airborne infectious agents.
- Protective PPE does not give ability to the staff to communicate, so they resort to using sign language. NHS staff sticks their full photos on their PPEs to give them a human face. It is critical to find a way of improving communication, without compromising on both healthcare workers’ own health and safety and impacting patient care.
- Connecting with patients and their families is both critical and yet more difficult than before. PPE including masks and face shields hide facial expressions, a tool for displaying empathy.
- The ICUs look terrifying with staff coming in with PPE; patients feel uncomfortable.
- Less chance to develop rapport with families because they are not often allowed to visit the patients and the staff has to wear PPE all the time.
- Families are contacted through phone and video calls for discussion.
- It is tough for the family members to see patient’s progression or deterioration in clinical state as they cannot visit hospitals regularly.

Team Communication:

- Communication among the staff who have not worked together before becomes uneasy, particularly in the COVID teams in the hospital.
- PPE makes it difficult to recognize the staff.
• Uses of stickers and names written on the surgical gowns have proved useful especially with acutely ill patients/ intubation etc.

Specific Problems of Remote Communication:
• Remote communication has become a quintessential part of health care sector.
• Loss of effective non-verbal feedback can have significant effects on patient engagement, compliance and outcome.
• It is found that communicating through video calls is easier as it has become a part of the routine in hospital.

Audibility Issues in PPE and Masks:
• Masks and PPE creates audibility issues.
• There is a constant need of deliberate silent pauses during clinical interventions and division of roles.

Challenges of Safety and Logistics:
• The hospital staff is always at risk while dealing with the COVID patients.
• COVID-19 outbreak has exposed significant glitches in health care supply chains which are complex and highly fragmented. Health care requires 5 categories of products i.e.; pharmaceuticals, personal protective equipment, medical devices and medical supplies.

What is NHS Blood and Transplant doing to overcome the challenges of COVID-19?
• NHS has started daily phone call system between 2 and 4 PM to connect with family members of the patients and COVID patients to make them feel acquainted and calm.
• Daily phone calls reduce the anxiety of the family members.
• COVID-19 Bereavement Helpline has been launched and is functional from 8 AM to 8 PM.
• Families are invited for virtual tour of bed space, tablet devices provided for the patients.
• Staff and nurses are provided with regular training on communication and professional development.
• Staff is provided with Help Guide for effective communication.
• Staff and nurses are provided with tool kits for safety and survival.

Findings:
• Non-COVID patients and families still have strict visiting policies in the hospital.
• Unfamiliar physical surroundings in ICUs as the staff have to wear facial mask and PPE all the time.
• Communication challenges during COVID times have affected the rate of organ donations.
• The law around organ donation in England has officially changed. As of 20 May 2020, all adults in England are now considered to have agreed to be an organ donor when they die unless they have recorded a decision not to donate. The country has now "opt out" system for organ donation.

Conclusion:
• COVID-19 has not greatly affected the organ donation scene in UK. People are still signing up for organ donation.
• There has been 3% increase in the rate of organ donation in UK since April, 2019.
• For now, and the foreseeable future, the implications of living with COVID-19 are profound. As NHS begins to consider the longer-term implications of the coronavirus, the reality is that a more sustainable approach to the communication challenges presented is required.

Questions/Comments:
Q: In terms of the access to the hospitals, are you stationed at hospitals like ICU or do you operate on regional basis. How do you get access to the hospitals?
A: NHS works regionally and has been working in different hospitals, where donations are happening. NHS keeps communicating with the hospitals about the plan, unit visit and safety precautions.
Q: Is the communication protocol being followed by all the hospitals uniformly?
A: As of now, the communication protocol is not being followed by all the hospitals. But NHS is soon going to organize a webinar on “Communication from behind the mask- medical and donation conversations” which would be open to all.
Q: Is consent rate for organ donation similar in UK and USA or has it dropped due to COVID-19?

A: As compared to pre-COVID times, consent rates for organ donation as well as tissue donation have gone up. It has been observed that families have understood the need and value of organ donation.

Q: As compared to last year, what are the absolute numbers of organ donation in UK?

A: There has been 3% increase in the rate of organ donation in UK since April 2019.

In the US, the number of organ donors has increased from 500 to 12,500, as compared to last year. 800 organ transplants have been performed in USA in the current financial year.

Session 3: Are we ready for Transplant Pregnancy Registries?

Chairpersons: Dr. Vivek Kute and Dr. Anil Kumar

Speaker: Dr. Nithya Krishnan

Dr. Krishnan began her lecture by stating that before answering the question of being ready for transplant pregnancy registries, it is important to understand why we are discussing pregnancy in transplantation; she also mentioned that as a nephrologist her talk would focus on pregnancy in renal transplants.

In 1956 a live transplant was performed between twins, from one sister to another. Following the surgery, both sisters – the donor and the recipient gave birth to five healthy babies in total. This gained attention and indicated that renal transplantation will not affect fertility. It also gave hope to many women suffering from end-stage renal disease to get a transplantation while have a chance at motherhood. Data available shows, two percent of women of childbearing age are able to conceive after transplantation and 75 percent of these conceptions continue safely and result in successful childbirths. Nevertheless, pregnancy in transplantation is not entirely risk free.
The risks could be classified as: (a) risk to the mother and (b) risk to the baby. With regard to the mother, while the risk of maternal death is low, other potential risks may include:

- Increased impairment in kidney function; particularly higher risk if the kidney functions were not normal at the onset of the pregnancy
- Worsening of existing proteinuria or newly developing proteinuria is common
- Developing gestational diabetes, pre-eclampsia or pregnancy induced hypertension (>10% risk in comparison to the general population)
- Possibility of acute rejection
- Urinary tract infections
- Risks multiply when factors like age, obesity, pre-existing diabetes and hypertension come into play

The babies on the other hand could be at risk for:

- Premature birth usually around 4 weeks earlier than the normal term delivery.
- In patients with impaired graft function to begin with, premature birth as early as 28 weeks even.
- Prematurity acts a causal factor for many other diseases including chronic kidney disease, cardiovascular disease and hypertension
- Congenital malformations if mothers were taking teratogenic drugs
- Renal disease if the mothers have genetically transmittable renal disorders.
- Neurological problems possibly due to prematurity which is seen later on in life of these children—subtle; difficult to diagnose

A study by Shah, et al, published in BMC Neurology, observed pregnancy outcomes in 4174 kidney transplant recipients and a total of 6712 pregnancies. Out of this 72.9% were successful live births, however, 21.5% had pre-eclampsia, 62.6% mothers delivered via C-section, 43.1% were pre-term births and there was acute rejection rate of 9.4%.

The ideal candidate for pregnancy and management of patients

For a woman who is a transplant recipient and wishes to get pregnant, it is essential to make the pregnancy similar to that of normal patient, so that the risks are similar.
The following factors would make a patient an ideal candidate for a healthy pregnancy:

- Normal renal functions
- No proteinuria
- Normal blood pressure
- No acute rejection or increase in immunosuppressant dose in the last 6 months
- Compliant patient on low immunosuppression
- 1-2 years since the transplant
- Not on teratogenic drugs (drugs that may cause malformation of the foetus)

In reality no patient would completely meet the above criteria and pregnancy is not a zero risk choice. It is essential that the patient is informed of all the potential risks as it is impossible to single out acceptable risk. Counseling the patient thoroughly and planning the pregnancy would lower the risks considerably.

The first step in managing pregnancy in a transplant recipient is to understand all risks, educate, counsel and plan the pregnancy with the patient. It is equally important to keep obstetrics and gynecology teams informed of the risks and involve them right from the beginning. Close monitoring, intense follow-up, early identification and treatment of complications are crucial. Blood, urine, proteinuria, blood pressures checks should be done frequently. As acute rejection is a possibility, many patients would require higher doses of anti-rejection drugs (even double the initial dose in some cases). As the immune system is heavily suppressed, transplant patients are at a higher risk of urinary tract infections and therefore frequency of checking the cultures has to be set accordingly.

Certain immunosuppressant drugs like Mycophenolate are contraindications and patients must be switched to something different. Drugs with FDA rating of D are contraindicated in pregnancy and therefore should not be used; Though Azathioprine is a class D drug, it can be used as the foetus cannot convert the drug to its active metabolite and hence cannot cause teratogenicity. Patients have to be laid off Mycophenolate for a minimum of 6 weeks to 3 months if considering pregnancy as they may result in miscarriages, abortions or malformations in the babies.

According to the Control of Hypertension in Pregnancy Study (CHIPS) study, the blood pressure has to be maintained at <130/80 mmHg. Drugs like ACEis and ARBs which are usually used in patients for maintaining blood pressure are teratogenic and hence should be stopped as soon as pregnancy is confirmed, (especially in patients who have proteinuria) or prior if planning is
possible. Management of pre-eclampsia has to be done in consultation with the obstetrician. Aspirin in low doses is used as a preventive measure.

Education, counselling and planning are the key in every scenario, irrespective of the degree of complication involved.

**Pregnancy in Donors**

Majority of the living donors are women; in 2015 in the US 63% of the living donors were women and 64% of these were of child-bearing age. There is almost always a 30% percent reduction of GFR in most donors and this may increase up to 50% in normal gestation. However, various studies conducted in this area (*Garg AX, 2015 and Davis S, 2019*) show the gestational diabetes and pre-eclampsia are more common among living donors in comparison to the general population. There could be a four-fold increased risk of pre-eclampsia, particularly in nulliparous and primiparous donors below the age of 30. Planning and appropriate counseling are essential for donors too.

Dr. Krishnan concluded her presentation by stating that transplant pregnancy registries are required.

**Comments**

Dr. Anil Kumar mentioned that registries are important for follow-ups and patients have to be counseled about contraception as well. Interventions have to be devised in cases involving male living donors too. Maintaining registries could help in developing best practices for ensuring healthy live births. Follow-up is crucial in case of patients who undergo transplants at the pediatric age. Registries could act as counseling guidelines for transplant coordinators who would be discussing parenthood possibilities with the patients and donors. Coordinators should be involved in data collection for the registry, compile best practices and they could also conduct research in this area using the collected data.

Dr. Krishnan emphasized the importance of involving the family in every step of the process and explaining all the risks and the possibilities of countering them.

Mr. Howard Nathan mentioned that the Transplant Pregnancy Registry International (TPR) was started in the US 20 years ago welcomes data from all parts of the world. He highlighted that the data recorded in the registry was instrumental in identifying drugs that may lead to miscarriages in 90s.
Session 4: Mini Research Projects for Members to Strengthen NATCO

Chairperson: Col. (Dr.) Avnish Seth and Prof. Gurch Randhawa

Speaker: Dr. Sunil Shroff

**Background:** Research project is an important tool to find evidence and possible solutions to a real problem. Before starting a research one should have a hypothesis on which one should build a framework. Dr. Shroff emphasized on the importance of conducting research projects in the area of organ donation as there is very little literature available and this can become the basis to help increase the organ donation rate in India.

**Discussion:** Research should be done to find the truth and to test a hypothesis. It contributes to the development and advancement of knowledge in a field.

Examples of successfully conducted research:

1. **Is Religion a barrier to organ donation?**

Hypothesis – it is not a major barrier

The Rajiv Gandhi Government General Hospital, Chennai conducted a single centre study on religion and organ donation between 2010 and 2014. In the five years, the hospital had certified 188 brain deaths out of which, 58 donations took place. Only 24% families of the total brain death certifications done in the hospital, refused organ donation on the grounds of religious beliefs. The study therefore arrived at a conclusion that religion is not a significant barrier to organ donation.

2. **Organ Donor Card – the important conversation with next of kin about one wishes**

Hypothesis – Does everyone carrying a donor card speak to next of kin about their wish?

Checking if the above statement was true and if they don’t, is there a solution?

MOHAN Foundation conducted an online survey to find how many people, who pledged their organs on the Foundation’s online registry, had spoken to their next of kin and informed them of their wish. With the objective to study the profile of people who do not inform their next of kin about their wish to donate after filling the online pledge form and to find a possible solution to the problem, emails were sent to 10,000 registered organ donors who had pledged their organs.

They were asked two questions:
• After your pledge, are you carrying the printed donor card in your wallet?
• Have you spoken to your next of kin about your online organ pledge?

A total of 1362 registered organ donors responded. Those who had not spoken to the next of kin were asked some questions over email and telephone. The result of the survey was that 953 donors (70%) were carrying printed donor cards and 1,212 (89%) had spoken to their family about their wish.

Another survey was done to identify the profile of the registered organ donors, who did not speak to the next of kin. It was found that those who did not inform their next of kin were men between 18 and 30 years of age. 65% people did not inform because they thought that it was not important, 25% hesitated to talk to their parents as they were not sure of the reaction, 20% stayed in hostels and felt it was best done face to face when they saw their parents and 15% felt that their religion might not support the decision.

Solution – Recommendations from the survey were to send a reminder email after a week to those who did not talk, requesting them to speak to next of kin and to introduce family donor cards so that all family members sign up together.

How to select a research topic?

• Choosing a topic that interests us is very important
• Brainstorm ideas
• Ensuring that material is available and can be sourced

How to conduct Research?

• Searching for preliminary information and reviewing existing literature on the chosen topic
• Locating sources, devise data collection methods
• Conducting surveys, interviews and experiments
• Establishing scope of research
• Collecting, analysing and interpreting data
• Finding reports, writing papers to present in conferences and seminars

Possible topics for Mini Research Project:
• Knowledge and acceptance of organ donation in different regions among different religions of India
• Understanding the value of standard protocols in organ donation communication within a hospital
• Nurses as partners to improve eye donation rates
• Reasons for mental stress among transplant coordinators
• Understanding the training needs of transplant coordinators
• Systematic review of funding sources for transplant patients
• Do Non-Transplant Organ Retrieval Centres (NTORC) improve organ donation rates?

A poll was rolled out to capture the profile of Transplant Coordinators who were in the audience. There were a total of 26 respondents and some major findings were:

• Most of the transplant coordinators work in NGOs
• Average work experience among transplant coordinators (5 to 10 years)
• Transplant coordinators are interested in research
• 62% of transplant coordinators have previous experience in research and most of them had been trained by MOHAN Foundation

**Pub Med**

Pub Med comprises more than 30 million citations for biomedical literature from MEDLINE, Life Science Journals and online books. Pub Med contains an index to every article from journals which are included in Pub Med. This is a good source to find research publications.

**Doing Research Projects: Things to Remember**

• Why is the research required?
• Choosing a central problem related to your field that you are passionate about
• What problems will the research address and solve
• Doing thorough literature review
• Choosing appropriate and effective research methods
• Knowing potential implications
• Seeking help from peers

Conclusion:

• The session helped the audience understand the importance of research and publications
• Publication and research is a team effort
• With help from MOHAN Foundation, NATCO and others researchers can improve their capacity and capability of conducting research and publications

Chairpersons' Remarks:

• Col. (Dr.) Avnish Seth remarked that the session was amazing and the quality of the topics chosen by Dr. Sunil Shroff were very good and informative
• Dr. Gurch Randhawa mentioned that Dr. Shroff had set out a very good framework, emphasising on the importance of publishing. The audience needs to realize that research and publication is a team effort and a lot can be achieved when we work together. He informed the audience that a protocol had been published on “how to do a systematic research” with the help of Institute for Health Research (IHR), University of Bedfordshire, UK, which is available on its website and people, who are interested to learn can download it for free. He said that IHR is ready to help people who want to take up research assignments and publish their work. Dr. Randhawa said that people across India can genuinely improve their research capacity and capability with the support of MOHAN Foundation and NATCO. He also mentioned how a former intern of the Foundation was doing his doctoral research in the UK under him. He encouraged others to be inspired by this success and aspire for similar positions in the future.

Inaugural Ceremony

Mrs. Lalitha Raghuram, President, NATCO welcomed the gathering once again and thanked the sponsors. She recollected the conference held at IIM Ahmedabad in 2019 and the interesting range of topics that were covered. Mrs. Raghuram requested the audience to observe a moment
Dr. Sunil Shroff congratulated all the speakers who contributed to the conference welcomed Dr. Farrokh Wadia of KEM Hospital, Pune to deliver the inaugural address and thanked him for his continued support to the programme.

Dr. Farrokh Wadia began his talk by greeting the audience and expressing his gratitude to the professional transplant coordinators. Highlights from his inaugural address:

- He was with the Zonal Transplant Coordination Centre (ZTCC), Pune from its origin and gave his tribute to Air Marshal Ramdas, the first chairman of ZTCC
- There was no support from the Government and therefore the progress of the deceased donor transplantation programme has been rather slow since then
- Mrs. Arati Gokhale, Central Coordinator, Zonal Transplant Coordination Center (ZTCC)-Pune has voluntarily taken path breaking efforts on the map of deceased organ donation in India
- Pune is the first city in Maharashtra to have shown considerable progress in deceased donor transplantation
- In most of the hospitals in Maharashtra, the transplant coordinators start their careers as medical social workers. This background has added great value to the role of transplant coordinators as they bring counseling skills, empathy, and knowledge aspects, while being impartial in all their interactions with patients and their families
- He himself has experienced the power of empathy many a times when convincing hesitant or resistant patients and families to willingly accept the concept of donation, whether it’s a live or deceased donor transplantation
- While ICU coordinators, nutritionists, and surgeons may bring valuable insights from their specialties, empathy and counseling skills are still vital. It is crucial for the doctors to get trained in these aspects
- The training programs for transplant coordinators conducted by MOHAN Foundation have been followed by ZTCC Pune. These efforts act as models for the less well-developed parts of our country
• There is no field in medicine, which is more fraught with ethical problems than transplantation. And he feels that this is where the coordinators should play a very important role

• The coordinator must be able to balance pressure from the family and the medical teams, always prioritizing the donor’s and recipient’s interests

• When it comes to deceased donor transplantation, the coordinator plays a more central role and the emphasis on the work would differ somewhat between the roles of a central coordinator and those of the hospital coordinators. The central person’s primary role is to ensure that allocation of organs is transparent and according to procedures

• The transplant coordinators face pressure from different quarters (political influence directed donations), particularly in high profile cases. In such scenarios their focus should be on fair allocation and the wellbeing of the patients

• There’s increased and unfortunate commercialization of medicine, which we are all aware of and a tendency might arise where the thin line between promotion and marketing may be breached

• It’s very important to remember that in transplantation, it is not the pursuit of numbers, which matters, but the interests and welfare of patients

Day 2 – 22nd November 2020

Session 1: Confusion over Coordination – an Ethical View of Organ Allocation
Chairpersons: Dr. Kishore Phadke and Dr. Kanthish R

Speaker 1: Ms. Arati Gokhale

The speaker started with the need for ethical allocation of organs due to the increase in number of transplant centers and the increased number of transplants that are being performed. She highlighted the points covered by the THO Act with regard to organ allocation. She mentioned that there should be no discrimination in the waiting list for patients and a system of regular audit to check the fairness of the allocation system should be introduced.

She also explained that in the ZTCC Pune region an early alert is sent within the region via WhatsApp which helps the Transplant Coordinators get their patients ready. They follow the system of local, followed by regional and finally the national patient list for allocation.

Speaker 2: Ms. Trilly Rachel Mathew

Ms. Mathew recalled that in the year 2020, Delhi-NCR has managed four donations. She mentioned that due to the COVID-19 pandemic, additional tests required for donors, recipients and even family members at times have made the coordination more difficult for retrieval teams.

She explained that an absence of clear protocol for alerting the authorities about possible organ donation – should a message be sent when a potential brain dead donor is identified, or when a clear consent is obtained from the family. This confuses the TCs in the hospitals to a large extent. In some cases the alert was sent after the 2nd Apnea test and hence there was very little time to coordinate, obtain cross match results, and the overall organ retrieval time was cut down significantly.

Ms. Mathew suggested the following to overcome confusions and make work more effective:

- System for early intimation, at different points in time from the TC of the donor hospital
- Allocation as per a scoring system set up by NOTTO - for Delhi NCR and for the regional team
- Adequate time offered to the recipient hospitals to prep a patient for transplant and to send the retrieval teams

Speaker 3: Dr. Amit Joshi
Dr. Joshi highlighted that communication issues, government issues, family issues and recipient challenges are the major areas where confusions arise in any organ donation case. He elaborated on how the lack of trained transplant coordinators could lead to poor communication among the hospitals. The SOTTO of Madhya Pradesh needs to develop better protocols to streamline the process, such as frequent updating of waitlisted patients, accurate reporting of brain dead patients, early intimation about a case, to name a few. Among the recipient issues, the main were language and dialect problems, financial assistance and the lack of clinician support for the patient.

**Comments/Discussion**

Dr. Phadke commented that most of these issues can be resolved by regular meetings with the hospital management and the state government.

Dr. Kanthimathy commented that in Tamil Nadu a group of patients who did not have funds available for a transplant, were classified aside in an “inactive” list, until the patients indicate that funds were available. The TC is responsible to maintain the waiting list (both active and inactive).

Ms. Gokhale recounted a case wherein even though the potential donor information’s was not shared with any Pune hospital TC, a Hyderabad hospital team had bought tickets to travel to Pune for heart and lung retrieval. She commented that there was communication among the top management about this case and this goes against the ethics of fair organ allocation. All TCs and transplant team members should be extremely careful about sharing information.

Ms. Ashtekar and Dr. Phadke mentioned that only SOTTO can allocate organs and there is a hierarchy and system of organ allocation that cannot be bypassed.

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**Session 2: Donation Protocol during COVID-19**

**Chairperson: Dr. Mathur S K**

**The US Protocol**
**Speaker: Ms. Susan Gunderson**

Ms. Gunderson began her lecture by saying that US was hit hard by the COVID during early March and April 2020, followed by a period of slowdown and then a spurt in cases again in the month of November. Over 12 million cases, with 255,076 deaths and 82,178 hospitalisations had been reported as on November 20, 2020. While the initial activity had been mainly on the east coast in New York and particularly in New Jersey, the present resurgence was in the middle of the country especially more in the rural areas of the United States.

Enumerating her experience on the donation activities:

- As per the data from UNOS, the deceased donation numbers were more this year as compared to 2019, which was quite extraordinary despite the impact of COVID. She attributed this to resiliency of the depth and sophistication of the donation system being followed in the United States.
- Transplantation activity was slightly down; a 2% decline in year-to-date transplants primarily affecting the living donor programme that almost came to a complete halt at the onset of COVID.
- An increase in the number of donations after circulatory death (DCD) - almost 25% of the total donations in the country, was reported.

**COVID-19: Responses and Protocols**

- **Leadership Context** – what’s important, for what was being done and how the work was going to continue, in other words the priorities were laid down. People were the highest priority, keeping the staff safe, keeping them safe from others, allowing them to work safely so that they were positioned to be able to be good stewards of their donation gifts and continue the mission so as to move forward to the future.

How one leads at the time of crisis is different from normal day-to-day leadership. It involves having a nerve centre or an integrated team that would focus on the crisis itself and responding to that. It’s cross-functional and the focus is on bringing together all the different functions that need to be addressed during this time.

Ms. Gunderson shared that in her organization, a COVID response team was formed and the team started meeting every day in the middle of March. It had a structured agenda to work
through the crisis contingency metrics that addressed different aspects like; space, staffing, supply chain, transportation, standard of care, communication and finance.

- **Clinical Considerations**
  - Essential providers - it changed in terms of clinical operations for managing organ donation, starting from the very top to go to the state or city officials to get approvals to be designated as essential providers so that the staff were out driving across the city and would not be pulled over by the police
  - Donor referral management were being done remotely
  - Hospital requirements – capacity, PPE
  - Donor screening and testing – was earlier a big roadblock as tests were not available and could not be done on time. It took a lot of coordination to ensure that the testing was in place
  - Case management – largely remote, partnering with local transplant centers on program status, accept guidelines and travel availability. This was achieved through constant communication with the transplant centers on a daily basis
  - Organ recovery – utilization of local recovery teams to minimise travel

- **Donor hospital access** – Ms. Gunderson shared that working with donor hospitals was a very important factor; a lot had been going as the hospitals were overwhelmed, short staffed and were facing PPE shortage and bed capacity issues with many restrictions. Ms. Gunderson’s organization used to have constant communication daily with the key hospitals to understand their needs and their capacity issues. The list of all the major hospitals in a particular service area, with their ICU bed capacity and overall capacity was updated weekly. This was basically done to understand as to how a donor would be managed on a particular day.

- **Business considerations** – Was moved to remote operations in the month of March and target dates were set till June 2021. Clinical operations were continued onsite with minimal disruption. Call centers, tissue and organ recovery centers continued to work. Technology resources were maximised to do remote work.

- **Lessons learned**
  - Act quickly, be nimble, adjust and revise as the landscape changes
- Communicate frequently and broadly – team communication was important because it was no longer in person and was all remote
- Recognizing that the first wave was not the only wave
- Relying on and serving your partners – partnerships were critically important along with communication
- Long term impact on donor pool – the donor pool patients who had COVID and recovered

The Indian Protocol

Speaker: Dr. Manisha Sahay

Dr. Sahay began her lecture by sharing that India is a country of multiple cultures, languages and religions, and close to 1.3 billion population. It therefore, was a unique challenge to make guidelines for our country that would cover all these aspects. The SARS-COVID-2 was first recognised in India in January 2020 and the latest figures of COVID-19 show that India has climbed up to second position after the US with regard to number of people affected by COVID-19.

In India, the main decision-making organizations to format the donation guidelines and protocol during COVID-19 are: The National Organ and Tissue Transplant Organization (NOTTO) under Ministry of Health & Family Welfare, Government of India, Indian Society of Organ Transplantation (Academic body) and Indian Society of Nephrology. The guidelines given by these three bodies allowed for emergency deceased organ donation, but the living transplantation was suspended from March till June 2020.

Guidelines and protocols

Before restarting the transplantation programme,
• Each transplant hospital should do a detailed assessment of epidemiology, current trends, surge capacity, impact of COVID-19 and assessment of ICU and team in respective hospitals.

• Check for access to drugs – patients should have the same stringent follow-up as they would have got prior to getting the COVID-19 infection.

• A COVID-Free Pathway – a team of Health Care Workers (HCW) consisting of transplant coordinators and transplant team members to exclusively cater to transplant cases so as to reduce the risk of transmission.

• Two transplant teams were suggested to work separately. These teams will have independent transplant surgeon, physician and intensivist so that all the surgical and medical problems can be handled if one team gets quarantined or exposed to COVID-19.

• Reserve personnel in transplant teams – in case a member needs to be quarantined, the care of the patient should not suffer.

• Mandatory donor and recipient consent including the possibility that the patient may become COVID positive post-transplant. It should also include risk and benefit of transplantation versus dialysis in case of renal failure.

• Availability of Personal Protective Equipment (PPE) as well as training in PPE as per government guidelines.

• Haemodialysis compliance for the COVID preparedness to be assured so that the recipient being dialysed should not become COVID positive before the transplant – a separate COVID negative unit to be reserved for these patients.

• Screening for COVID-19 to be made mandatory for donors, recipients, HCW and care takers. Screening on the basis of clinical symptoms, epidemiology (travel history, history of contact and confirmed diagnosis of COVID-19 in the last 28 days), Laboratory screening (RT-PCR test, chest CT scan of donor).

• For a COVID positive donor – to wait for 3-6 months because the long-term outcomes of COVID-19 infection are not known. In case of life-saving transplants, the donor can be accepted if completely symptom free for 28 days with two documented COVID negative tests.
• Social distancing norms to be followed by the donor and the recipient two weeks prior to the surgery.

Transplantation and beyond

• Surgery – during surgery minimize the use of energy devices, avoid the ultrasonic scalpel, if energy is needed and lower energy settings to minimize surgical smoke.

• Post-transplant inpatient protocol and OP follow-up
  - Post-transplant immunosuppression guidelines are the same as for a non-COVID patient. But, if the patient becomes positive then CNI to be reduced and MMF to stop as done by ERA-EDTA.
  - Restrict movements – restrict movement of recipient to other hospital areas, use of designated potable x-ray or other diagnostic equipment; if transport mandatory then predetermined transport routes should be taken to minimise exposure. Patients to wear surgical masks and health care workers should perform hand hygiene and wear surgical masks while transporting patients.
  - Equipment – disposable ones to be recommended, and if they need to be re-used then they are to be disinfected using ethyl alcohol 70% or 1% sodium hypochlorite.
  - Waste disposal as per the infection prevention guidelines.
  - Post-transplant visitors – there is a limit to the entry of visitors and a visitor track record is to be maintained.
  - Routine cleaning and disinfecting of surfaces that the patient comes in contact with, using 1% sodium hypochlorite.

• COVID infection post-transplant – The treatment is as per the local authority guidelines as there are no standard accepted treatment guidelines. The transplant teams should make case by case evaluation for dose adjustment to balance infection control and rejection.

Telemedicine – While it may not be a substitute to in-person consultation where a clinical examination is required, telemedicine is feasible to encourage social distancing.
The AarogyaSetu App promoted by the Government of India, is a contact tracing, syndromic mapping, self- assessment mobile app that gives the status of COVID-19 patients. The transplant patients are recommended to use this app post discharge from the hospital.

Dr. Sahay concluded her talk with the following remarks:

- Transplant is possible in COVID pandemic
- Depends on resources available
- Screening for COVID
- Consent from donor and recipient
- Separate teams
- Immunosuppression same as non-COVID
- No effective therapy if COVID infection (Fluids, anticoagulation, oxygen, non-invasive ventilation, steroids)
- Follow – mask, hand wash, social distancing

Questions/Comments:

**Q:** How did you achieve the increase in deceased organ donation in the COVID-19 times?

**A:** Ms. Susan Gunderson – It has been achieved through the ability to move quickly to different processes to have donations happen, and it’s been different in each area of the country. It’s the way that the conversations were happening with the hospitals, with the care teams and moving very quickly. Because of the pressures on the resources, cases were shorter than they had been. They were able to come through it mostly by functioning efficiently.

**Q:** Is there a need to sanitize the recipient waiting list?

**A:** Ms. Susan Gunderson – There were serious discussions about patients who should be transplanted and who should not. This may be actually a long-term improvement for the system overall, that the programs are more attentive to that discernment about which patients can be put at the risk for transplantation. This could be a long term improvement in just how the processes should run.
Comments

In India, donations during COVID period were much less as compared to last year.

Dr. Manisha Sahay – In the initial months of COVID infection, we were skeptical and scared to do transplants because of the risk of infections, limitation of our resources, less Nephro work force and skewed doctor-patient ratio. Another contributing factor was the figures from the west, where in-spite of a good system in place, the mortality rate was 30%. But then in the post unlock phase things started to pick up. And, as is seen in India if one center does something the others follow suit. Now many centers have started multi organ transplants.

The centers which were very well equipped and had patients from higher socioeconomic strata, took up the transplant programs earlier as compared to the public sector hospitals. It was easier to get those transplanted where these issues could be easily taken care off. Somehow the public sector hospitals have been lacking and lagging behind in our state though they have started doing it now.

Session 3: A Walk in My Shoes: A Transplant Coordinator’s Recovery Story after COVID-19 Infection

Chairpersons: Dr. Muneet Kaur Sahi and Dr. Sholay Meitei

Speaker 1: Mr. Ahsan Ullah Ansari

Mr. Ahsan began by thanking NATCO and MOHAN Foundation for inviting him to share his experience of being infected and recovering from COVID-19. He mentioned that the Corona virus affected people physically, mentally, socially and financially across the globe. Mr. Ahsan shared his story of getting infected by the virus during management of a COVID positive patient.

- After four days of contact with the COVID-19 positive patient, on 14 June, 2020 symptoms like fever, fatigue, loss of appetite, skin rashes and headache appeared. Mr. Ahsan isolated himself for the next four days and consulted his doctor who advised symptomatic treatment but his health deteriorated on the night of 18 June, 2020. He said that this was the most horrific night as he could barely breathe and felt restless. He was continuously thinking of his daughter and family. Somehow he managed to spend the night by taking
long breaths. Early morning, he contacted his colleague who helped him in getting admitted to a hospital.

- After admission the doctors started symptomatic and supportive treatment and advised him to eat healthy, drink hot soup and plenty of water. Mr. Ahsan said, to avoid depression during the hospital stay he shifted his focus on work and received a lot of moral support from his family, especially his father. He was hospitalized for 10 days and on day 11 he was discharged.

- During Mr. Ahsan’s stay in hospital his family faced lot of difficulties as he lives in a joint family and has to support 16 members altogether. His three brothers lost their jobs during the pandemic and all their savings were exhausted. But it was his will power and belief in God that kept him strong during these tough times. He believed and encouraged his family by saying that sooner or later things will change for good.

- Mr. Ahsan recalled the happiest moment after discharge from hospital, when the billing manager and pharmacy manager refused to take the money on the directions of the hospital director which was approximately 80,000 INR.

- Mr. Ahsan shared some protective measures we all need to take during these times: cleaning of hands very often, avoid touching your eyes, nose, and mouth, not to spend time at crowded places, avoiding close contact with a person who is unwell, covered coughing or sneezing and disinfecting frequently touched objects and surfaces.

- Mr. Ahsan at the end thanked Mr. Vijay Saxena (Director- Smart City Hospital, Bhopal), Dr. Abhay Tyagi (Director, Smart City Hospital) and his colleague Mr. Mushtaque Ahmed Qureshi, who during these tough times stood by him like a family.

**Speaker 2: Mr. Ciju Nair**

Mr. Ciju shared his experience of getting infected with COVID-19 and the only symptom that showed up was body ache.

- Mr. Ciju revealed that on the evening of May 5, 2020 he experienced a mild body ache. So next day he went to the hospital Flu Clinic and got COVID test done. At that time it was the hospital policy that even if slightest symptom occurred one has to undergo COVID
test. On May 7, 2020 the report came as positive. As he was sharing a room with another person, he asked him to get the test done as well, but turned out to be negative.

- Mr. Ciju was hospitalized from 8\textsuperscript{th} May to 19\textsuperscript{th} May, 2020 at MGM Hospital, Kamothe since the hospital he was working with was a non-COVID center and the positive patients were to get admitted in the Municipal Hospital for treatment. During these 10 days, he considers the day second to be the most stressful day because of the COVID sticker that was labeled by Panvel Municipal Corporation at his door. The society in which Mr. Ciju resided was also quarantined and there was panic among residents of the society.

- During the hospital quarantine, Mr. Ciju said to keep himself busy and active; he meditated and took an evening stroll every day. He even coordinated three deceased donor organ donations during this period of quarantine. He did not inform his family since his wife was expecting and it was her fifth month. He had only informed his brother and asked him to keep it confidential.

- Post discharge, as per guidelines during that time, if a person was asymptomatic for 10 days he needed to be home quarantined for 7 days and no COVID test was to be repeated. Mr. Ciju was not allowed to enter in the society as the residents wanted him to undergo COVID test again. Following negotiations with the society’s head and his doctor’s intervention, Mr. Ciju was allowed to enter his society late at night after all the confusions were cleared.

- Mr. Ciju resumed his work on May 29, 2020 and was blessed with a baby girl in September. Post COVID recovery, he has donated plasma five times.

**Comments**

At the end Dr. Sholay remarked that these narratives were great examples for the saying, “\textit{when times are tough, heroes emerge}.” He further said that these two heroes/frontline workers were COVID-19 survivors who made deceased donations possible even during these unprecedented times. He wished both of them a safe future and hoped they will make a difference in the transplant community.
Session 4: Increasing the Donor Pool during the Pandemic

Chairpersons: Dr. Sanjay Kolte and Dr. Noble Gracious

Speaker: Ms. Arati Gokhale

Ms. Gokhale began her talk by sharing with the participants that their organization did not coordinate any donation in the months of March and April 2020 due to the lockdown imposed because of COVID pandemic. However, from May onwards they have carried out 18 organ donations till date and 32 in the whole year.

The highlights of her talk were:

Organ donation most commonly follows death that results from a severe brain injury or a critical event. A decision to withdraw or withhold intensive care measures can be challenging especially in different hospital set ups, different regions and because of different cultural, religious and social factors.

Issues and challenges

- High demand for transplants (demand versus supply gap)
- Poor infrastructure, particularly in Govt. sector hospitals
- Poor rate of brain stem death certification by hospitals
- Poor awareness and attitude towards organ donation – low deceased organ donation rate
- Lack of organized systems for organ procurement from deceased donor
- Maintenance of standards in transplantation, retrieval and tissue banking
- Prevention and control of organ trading
- High cost (especially for uninsured and poor patients)

Deceased Donation: current methods to improve donation pool

Improve organ donation awareness through:

- Media: Newspapers, Social media awareness, Radio & TV programmes
- Activities like marathons and street plays
• Rotary clubs at local level
• Festivals, cultural programmes
• State-wide film competitions on organ donation theme
• Online activities – especially during the pandemic time as this is the most powerful tool to increase awareness

Donor hospitals
• Identify local hospitals and register them as organ procurement centers
• Training staff at local hospitals
• Intensive care help
• Resources
• Communications

Transport
• Green Corridor
• Talks with flight agencies
• NGOs involving retired pilots

From the very beginning
• Early recognition of severe incapacitating brain injury situation
• Involving the coordinators and social health workers early on
• Special resources – dedicated health professionals to optimize donors
• Organ donor funds to help donor family financially
• Provide religious, cultural, social support for funeral, post donation and follow up

For Coordinators
• Train and engage organ donation coordinators in empathy, creating a bond and relationship with donor family
• Understanding the families’ needs, grief, misgivings, misunderstandings, helping them tide the crisis
• Involving social, psychological support, religious support, respecting traditions and allowing them time

• Facilitating religious and end of life process until funeral/burial arrangements.

Intensive care

• Continued engagement of the intensive and emergency care communities

• Ensuring that their patients are always given the opportunity to donate their organs after their death when this is a possibility.

• Specific legal, ethical, professional and organizational considerations of every scenario to be addressed for each region.

Organ donation methods

• Encourage the population to carry the donor cards

• Register on the national online registry (NOTTO) so that their wishes with respect to donation are known

• Non-heart beating donation: DCD donors to be tapped

Transplant teams

• Expanded criteria donor acceptance

• Marginal donors, high risk donors

• Avoiding organ wastage and surgical injury to deceased organs – accountability

• Allowing for quick and efficient testing measures like ultrasound, biopsy, cross matching etc. to be available at donor site

Organ viability

• Use of perfusion techniques to assess marginal organs or preserve organs for an extended period of time to allow for travel or for surgery

She concluded her talk with the following remarks:

• Organ donation rates are improving and yet thousands die waiting for an organ

• There is an urgent need to consider factors which will increase the donor pool

• Optimize policies and legal guidelines to allow for ease of organ donation
• To integrate and interact across the world to understand different useful methods

The goal should be to save lives through transplantation, support the family’s choice and honor the patient’s wishes.

Comments

Dr. Sanjay Kolte: COVID has really worked towards connecting the world in a better way. A transplant coordinator is one very key person who can make a difference to the deceased donor program of a region or of a hospital. When the brain stops functioning in a brain-dead patient, the heart keeps beating. As long as the heart is beating, the organs are good for perfusion and good for utilization. Similarly, as long as the transplant coordinator is aware and perseverant, the possibility of converting a brain death into retrieval is very high. To emphasize on this, he gave the example of Pune ZTCC doing so well in donations and congratulated Ms. Gokhlale for it and showing to the world that even a deterrent like the pandemic can be exploited to increase the rates of donation.

Dr. Noble Gracious: The main challenge in increasing the donor pool is lack of certification. The problem is not donation but brain death determination. This concept has to be incorporated in all ICU’s and with all the intensivists. For the last 20-25 years the same things are being done and repeated; once the family gives consent for organ donation then death determination is done, it should be the reverse, brain death needs to be certified irrespective of organ donation.

Session 5: Patient Support during the COVID Pandemic

Chairperson: Dr. Niroshan Seneviratne

Transplant Coordinator Driven Approach

Speaker: Dr. Sujata Rajapurkar

Dr. Rajapurkar spoke on the Transplant Coordinator driven approach with respect to patient support during COVID pandemic. She shared that there are 355 hospitals that are registered for only kidney transplant in the country and about 34 for harvesting of organs. According to Indian Association of Transplant Coordinators, 250 transplant coordinators are employed in hospitals.
Apart from transplant coordinators, many NGOs, qualified Medical Social Workers and volunteers are also involved in providing support to patients during the COVID pandemic.

The main highlights of her talk regarding TC driven approach were:

- **Counseling – most important aspect of supporting the patient**
  - Assessment
  - Screening for Depression
  - Assessing Quality of life
  - Behavioural changes: following safety precautions, wearing mask, avoiding crowded places
  - Following diet and fluid restrictions
  - Taking regular medication and consulting many doctors

- **Education – another important factor to consider**
  - Pre-transplant – nutrition, maintaining dry weight on dialysis and immunizations like hepatitis B and influenza
  - Post-transplant – medication and treatment adherence, diet and fluid adherence, encouragement for regular exercise and follow-up
  - COVID related education – proper use of N95 masks, face shield and hand sanitizer, social distancing, home-lab collections, using tele-consultations effectively to avoid unnecessary visits to hospitals, contacting the primary doctor in case of suspicion of COVID-19 infection, vaccines and COVID related medications only after consultation with doctors and avoiding self-medication.

- Coordination with multidisciplinary team members
- Help find suitable accommodation, food, transport near the center
- Help collecting financial resources
- Hand holding and providing shoulder to lean on
Transplant Coordinator planning patient support activities

- To stay active (plan fun-filled activities)
- Encourages to pursue hobbies like Art/craft/cooking/writing/listening to music
- Brain challenging games like – solving crossword puzzles, memorizing songs/religious bhajans
- Connect with relatives, friends and neighbours
- To take help when needed, give help, be kind to oneself and others, volunteer for social activities and to remain happy
- To keep adequate stock of medicines at home, not to miss treatment and adhere to test schedules
- Donor support activities – plan face time or virtual meetings to connect, educate, send appreciation card/letter and encourage and empower for regular follow-up near the residence

Caregiver support activities – There may be risk factors for caregiver; ‘stress’ that may include being a female with no formal education or having financial difficulties, difficulty in solving problems and lack of coping skills. So, to cope and give support by:

- Accepting help
- Focusing on oneself and by education
- Setting realistic goals: breaking large tasks into smaller tasks, prioritising, establishing daily routine, planning by making a work to do list and saying ‘no’ to activities that are mentally draining.
- To stay connected by joining some support group
- Setting personal health goals that include good diet, nutrition and exercise
- Involve the patient to complete insurance formalities on time
Group Driven Approach

Speaker: Ms. Jaya Jairam

Ms. Jaya Jairam began her talk by revealing that earlier this year in September, 2020 MOHAN Foundation launched a patient support group initiative called TRIOMPH, an acronym for Transplant Recipients of India and Organ Failure Patients - a movement to provide hope.

The main highlights of her talk regarding group driven approach were:

1. TRIOMPH – *Mission and Objectives*
   - It is committed to improving the quality of life of organ failure patients, transplant recipients and caregivers through education, support and awareness.

2. A Unique Initiative – *Of the Patients, By the Patients and For the Patients*
   - A very unique initiative, primarily because the chapter leads are from the patient community themselves, and will be leading the various initiatives in their respective geographical areas across the country by guiding others ‘how-to-work.’

3. Pain Points – *Especially during COVID times*
   - Identified and realised the pain points of this patient community. At the center is the patient community comprising of organ failure patients, transplant candidates and recipients.

   - The large pain point is the financial burden as the treatments are expensive, ongoing and lifelong as post-transplant, patients need regular follow up and have to take immunosuppressants lifelong to avoid organ rejection.

   - Transplants are expensive and cannot be afforded by everyone.

   - Employment and livelihood challenges - as due to pandemic, the economy is down and this patient community has a specific set of needs due to their health conditions.

   - All these pain points have caused a lot of anxieties. A dialysis patient needing to go out for haemodialysis is exposed to COVID risks; the situation is similar for transplant recipients who are immunocompromised and if they contract COVID as treating them would be challenging. There is also a fear of losing jobs as this community of patients is not easily able to move out due to pandemic. Also does not look like there is a light at the end of the tunnel. Sadly, all these pain points are interconnected and each one causing anxiety and adding misery to the patient community.
4. Priority Solutions

- To reduce the financial burden, tied up with a Diagnostic Aggregator which will provide 25% discount to patient community for investigations. It is a pan-India comprehensive network of 100 plus cities. User has the choice of selecting his/her local diagnostic provider while sitting at home.

- To help dialysis patients minimize COVID exposure risks by providing home dialysis.

- Not getting an organ on time is challenging but making transplants affordable is equally challenging. To make transplants affordable Ms. Jaya said that they have tied up with likeminded partners like Transplants ‘Help The Poor’ Foundation and Edelweiss Tokio Life Insurance through which funds will be raised to support the transplants of under privileged patients.

- Creating employment and livelihood opportunities for patients relying on dialysis, organ failure patients with co-morbidities as well as transplant recipients who are immunocompromised. This community of patients cannot travel to their work place due to risk of COVID infection and hence losing jobs is inevitable. A survey taken revealed 70% of this patient community were unemployed and 55% of it had previously held job roles like Vice President Technology, System Administrator, 3D Designer and Programmer and so on. The point is that this category of patient community has necessary technical skills. So to bridge the gap between the corporate and patient community we started sensitizing corporate on diversity and inclusion and special needs of this patient community. This proved fruitful as many corporates became open to recruit people from this community. Not everybody from this patient community will fit into the corporate set up so next step would be to enable skill development for livelihood. This initiative is in partnership with likeminded NGOs like Amar Gandhi Foundation and Transplants ‘Help The Poor’ Foundation.

5. Call to action – Collaborate with You

- Would like to collaborate with NATCO members since TRIOMPH is an independent support group and helping patients will make them feel that they belong to a larger community.

- Ms. Jaya ended her topic by saying that TRIOMPH is based on African Ubuntu philosophy which says, ‘I am Because We Are.’ It simply talks how about how humanity is inter-
related and how I depend on you all and you all depend on us. This is how we have to join hands to go ahead and move out of the present situation.

For Underprivileged Patients
Speaker: Mr. C.Y. Pal

Mr. Pal began his talk by congratulating all the transplant coordinators for playing a very important role in promoting organ donation as without it the transplant programme will not take off both in the short and long term.

He emphasized on two critical elements that are part of transplantation - availability of organs and availability of money. His organization, Transplants ‘Help the Poor’ Foundation was primarily dealing with availability of money, particularly for the poor and underprivileged.

The main highlights of his talk were:

- Mission of the Foundation to help save lives of underprivileged people in India who need and cannot afford lifesaving transplants.

- Objectives of the Foundation: provide financial help to the poor for liver, kidney and heart transplants, promote organ donation by building awareness and introducing many initiatives similar to JEET (Joint Effort to Enable Transplants), and working together with all possible NGO’s towards the objective of helping poor people for transplants.

- Patients admitted in various hospitals like Apollo (Navi Mumbai), Global, Jaslok & Saifee, Sahyadri in Pune, Aster in Bangalore, Manipal Hospital in Manipal, Dr. Rela Hospital & Institute in Chennai, Medanta The Medicity in Gurugram& Fortis Hospital in Delhi have benefitted from this programme.

- The Foundation has helped 163 patients (98 liver, 59 kidney & 6 heart transplants) and raised 5 crores.

- Even in COVID times, the current year, requests for transplants had reduced in the initial three months but they picked up subsequently and presently the Foundation is helping 8-10 patients every month.
Future goals/task ahead: by March 31, 2021, 200 lives to be saved and by March 31, 2023, 500 lives to be saved. Funds to be raised by March 31, 2021 INR 6.5 crores and by March 31, 2023 INR 20 crores.

Transplant Coordinators play a very important role in this whole process.

The Foundation has five trustees, out of which one of them is a distinguished, world-renowned liver transplant surgeon and the other 4 are from the business community. The Foundation raises money through their business community contacts asking corporates and high-profile individuals for help and through crowd funding.

Session 6: Indications for Lung Transplantation with special reference to COVID Infection

Chairpersons: Dr. Sanjay Dixit and Ms. Sujata Ashtekar

Speaker: Dr. Sandeep Attawar

History of Lung Transplantation

Between the early and 1960s and 1980s around 44 attempts were made at lung transplantation and none were successful. Lack of effective immunosuppressants and issues related to bronchial anastomosis were the main deterrents. The discovery of Cyclosporine turned the tables and paved way for a series for successful lung transplants starting with a heart-lung transplant in Stanford in 1980. This was soon followed by single lung and double lung transplants in 83 and 86 respectively, at University of Toronto, which since then has been a leader in the area, performing around 200 lung transplants every year.

Identifying a Candidate for Lung Transplantation

Patients with advanced lung diseases, with deteriorating clinical condition despite medical and surgical therapies may be referred to a transplant center by a pulmonologist. These are patients whose daily activities are restricted and life expectancy of less than two years, if untreated. While not all patients referred would be requiring a transplant, early referral is crucial as it would help in identifying and managing the modifiable risk factors (may include diabetes, hypertension,
obesity) thereby facilitating progression to lung transplantation. Controlling the comorbidities and help patients live a better quality of life will be the focus of the professionals in an advanced lung care facility.

Is it essential to understand that lung transplantation is not a cure by itself, but is only a treatment modality. Listing a patient for transplant should be a decision arrived at following discussions between the patient, caregivers and medical professionals. The objective of a transplant should be long-term survival and better quality of life for the patient achieved by way of good organ function, adequate immunosuppression, careful monitoring for rejection, long-term follow-up and importantly patient compliance.

The International Society for Heart and Lung Transplant has published guidelines for candidate selection. The following criteria are generally considered when listing a patient for lung transplant:

- >50% risk of death within 2 years of onset of lung disease if transplantation is not performed
- >80% probability of survival for at least 90 days after the transplantation
- >80% possibility of 5-year post-transplant survival, given that the graft functions well

Lung Transplants – The Present Scenario

The number of both adult and pediatric transplants performed all over the world has witnessed a steady progress, not only in North America and Europe, but other countries as well. 80% of the lung transplants performed in India are to treat the following conditions: (a) ILD (Interstitial lung disease); (b) PAH (pulmonary hypertension; resulting because of untreated congenital heart diseases in children); and (c) Bronchiectasis (subsequent to tuberculosis or other infections). In contrast, in the rest of the world most transplants are performed in case of: (a) Chronic obstructive pulmonary disease (COPD); (b) Idiopathic pulmonary fibrosis (IPF); or (c) cystic fibrosis (CF).

Double lung transplants have almost entirely replaced single lung transplant procedures and are considered the go-to procedures for patients with end-stage lung diseases like ILD, who are medically untreatable. Worldwide, most centers perform an average of 30 lung transplants per year, and only about 15 centers perform more than 50 per year (KIMS is one such center).
The average survival rates following a lung transplant in case for adults is 6.2 years whereas it is 5.7 years in children. However, children who have survived a double lung transplant continue to be better as years progress, requiring fewer interventions as compared to adults (Kaplan-Meier).

**Contraindications to Lung Transplants**

Relative criteria:

- Age >65 years with poor physiological reserve
- Obesity
- Malnourishment
- Weak bones
- History of chest surgeries
- History of mechanical ventilation/life support (ECLS) (there are exceptions)
- Severe viral/bacterial/fungal infection of airway
- Patients infected with Hepatitis B/C (may require a multi-organ transplant)
- Patients with HIV (clearance required from immunologists)

Absolute criteria:

- History of malignancy (<5 years)
- Multi-organ dysfunction
- Extensive/multiple arterial blocks
- Acute/chronic infections (sepsis, liver failure)
- Active TB; poorly controlled viral infections
- Recent cardiac arrests
- Bleeding disorders
- Severe spine deformity
- Class II/III obesity
• Additionally, patients exhibiting certain psychiatric conditions, noncompliance with the treatment regimen, substance abuse or poor rehabilitation potential are not considered

**Clear Indications to Consider Lung Transplant**

**Interstitial Lung Disease (ILD)** or Pulmonary Fibrosis: scarring or inflammation of the interstitium; makes breathing difficult. A biopsy or CT scan could be done to diagnose. Reduced forced vital capacity, shortness of breath, oxygen requirement even if only minimum exertion and diminished carbon monoxide levels could be symptoms and patients should be referred to a transplant center. Rapid progression and worsening of symptoms including rise in blood pressure in the lung are indicators that the patient might require a transplant early.

**Pulmonary Vascular Disease:** may cause permanent and irreversible damage to the pulmonary vascular bed. A rapidly progressive disease and symptoms may include inability to walk, coughing up blood, tiredness and breathlessness. An echocardiogram or cardiac catheterization would be required to diagnose. A huge population in India suffers from this disease and early identification is not possible in most cases.

**Bronchiectasis:** permanent enlargement of parts of the airways of the lung; could result because of uncontrolled tuberculosis. Chronic cough with mucus production, shortness of breath, coughing up blood, and chest pain are the symptoms. Early referral is the key. They need to be listed for a transplant when their lung functions rapidly decline oxygen levels go down and they require frequent hospitalization.

**Chronic Obstructive Pulmonary Disease (COPD):** emphysema and chronic bronchitis are the most common diseases; usually diagnosed in smokers. Lung resection could be a possibility in a few of these patients, while others may require transplant as the disease progresses. The BODE score is a clear indicator for transplant listing. A slowly progressive disease and not many Indians diagnosed with COPD require a transplant.

**COVID Infection and Lung Transplantation**

While lung is the entry point for the viral infection transmitted through contact and droplet, it may affect other organs of the body making transplantation highly difficult in infected patients. Around 1030 lung transplants have been performed in US in 2020. The degree of mortality has been extremely high around the world and many infected patients die before a chance at transplant; there is also a dearth of qualified medical professionals to care for these patients.
Indications for transplants in COVID affected patients may include:

- Confirmed irreversible respiratory failure
- When medication, mechanical ventilation and ECMO have failed to improve lung function
- Virology status has been confirmed negative through consecutive nucleic acid tests
- Absence of dysfunction in other organs that is untreatable

The Lancet has also come with guidelines for when to consider lung transplantation in COVID infected patients, emphasising on the negative test results, rehabilitation potential of the patient and the experience a transplantation center should have to handle high-risk transplants in addition to general criteria.

Unfortunately, the regular patients in the waiting list have been pushed owing to emergency transplants that the COVID patients require. In a COVID infected patient the lung almost resembles a brick, unlike its feather like texture in a normal person.

Dr. Attawar gave examples of the recent COVID transplant surgeries he has performed, in one of which the patient was on ventilator for 2 months and on ECMO for 24 days and more recently for a patient who was on ECMO for 58 days.

It has been a challenge for the transplant professionals to manage the slew of patients arriving with varying degrees of illness. It requires a whole army of healthcare workers to work together to deal with the situation. The lung transplant programme over the last 50 years has proved very successful and abundant knowledge has been gathered to enhance to programme. However, COVID-19 has decelerated this progress significantly, forcing professionals to make exceptions which otherwise would be considered contraindicatorory. It has also raised the question of ethics and organ justice as the non COVID are being denied organs.

**Comments/Questions**

Ms. Sujata Ashtekar commented that from a time when patients had to call and ask if lung transplants were possible, we have come a long way, thanks to the extraordinary efforts of Dr. Attawar and his colleagues.
Q: Has the cost of lung transplant increased?

A: Yes, it has unfortunately increased significantly. While awaiting a transplant, the cost per day for a patient of ECMO or ventilator could be around one lakh rupees. Despite bearing such heavy costs and hoping for recovery, it becomes difficult to let families know how the selection for transplant is made and at certain times it is impossible to explain certain issues to them (choosing a younger individual over an older patient); this has been disheartening. Dr. Attawar's team of transplant coordinators have been doing a great job interacting with multiple families focusing on the emotional and psychological aspects.

Q: How many COVID related lung transplants have been performed in India so far?

A: Dr. Attawar’s center has performed six so far – three of which were for COVID purely and three others for patients with lung disease who contracted COVID, became sicker and went on life support. Credit must be given to all organ procuring organisations and donor coordinators have continued to do their job even during these challenging times.

Q: Are primary lung cancer patients candidates for a lung transplant?

A: No

Q: Any risk to the surgical team involved in COVID lung transplant procedure?

A: Almost half of Dr. Attawar’s team contracted COVID from just donor retrievals; partner hospitals helped them balance the absent team members.

Dr. Attawar made a request to get as many consents for lung donation as possible given the huge number of patients waiting for an organ all across the country.
Session 7: Women in Transplantation – Some Memorable Journeys

Chairperson: Dr. Promila Gupta

Speaker 1: Dr. Nancy L. Ascher

Highlights from Dr. Ascher’s talk:

- When she was in medical school at Michigan, there were barely any women surgeons to be considered as role models
- Despite the societal influences, she chose to opt for the field of transplantation, and that she is happy today for having taken such a decision
- In lieu of her retirement, the COVID pandemic has presented her an opportunity to help many people
- She was the first woman to have the opportunity to perform a liver transplant after learning from Dr. Najarian and from Dr. Starzl (well-known leaders in the field of transplantation)
- She began the liver program at the University of Minnesota and following that she decided to move to the University of California, San Francisco, where she led the transplant team from 1988 to 1999 and became the Chair of the Department of Surgery. In the same period, she became president of the American Society of Transplant Surgeons, and was involved in The Transplantation Society through which she became one of the founders of the Women in Transplantation (WIT) initiative
- Women in Transplantation is a political movement that has been very keen on placing women in positions of leadership within the transplantation community
- Across the globe, only 140,000 transplants are performed in a year (accounting for only 10% of the need), which is grossly underestimating the need
- After COVID people may begin worrying about the non-communicable disease and this would mean that we have to consider transplant as part of the armamentarium of helping the end-stage organ failure patients
- Dr. Ascher is still an active transplant surgeon, continuing to perform both live and deceased donor liver and kidney transplants at her institution, irrespective of her age and finds this extremely gratifying and stimulating
When she was the Chair of the Department of Surgery, 40% of the department was comprised of women and half of the surgical residents that were training were women.

Speaker 2: Dr. Lori Jeanne West

- She comes from a pediatric cardiology background and has done her Ph.D. in transplant immunology, under the supervision of Dr. Kathryn Wood and Dr. Peter Morris after she took a break from clinical medicine for four years.
- She had faced a lot of challenges in establishing her career in the field of medicine, despite which she managed to finish her training in transplant immunology.
- She constantly fought for her right in pursuing her dream of becoming a clinician-scientist and has served as one for more than 20 years and is still looking forward to it.
- About 10 years ago she became involved in the launch of a national program in Canada, the Canadian National Transplant Research Program of which she is the Scientific Director. She is gratified that there was equity at all levels in terms of women’s participation in building this program.
- New programs have been launched, more specifically, to help look into women-oriented challenges in different parts of the world, particularly in the field of transplantation.
- She was happy to meet Mrs. Lalitha Raghuram and know about the work done by MOHAN Foundation during her visit to India.
- She ended her address by mentioning a quote, “The reasonable man adapts himself to the world. The unreasonable man insists on trying to adapt the world to himself. Therefore, all progress depends on being unreasonable.” by George Bernard Shaw.

Speaker 3: Dr. Vasanthi Ramesh

- She is thankful to The Transplantation Society for having given her the Unsung Hero in Transplantation Award.
- She had completed both her under graduation and post-graduation at Stanley Medical College, Chennai and was the best outgoing student of her college.
• Her husband and in-laws have strongly supported both her personal and professional development

• In 2014 she was appointed as the first Director of NOTTO

• The NOTTO website was launched 8 years ago and a major upgrade is underway

• She is very happy to share that India holds the third place in the total number of transplants performed globally and affirmed that efforts will be taken through the guidance of TTS, WHO and taskforce members to push India forward in increasing deceased organ donation rates

• NOTTO, besides celebrating its achievements, most importantly honours the donor families as part of observing the National Organ Donation Day. Celebrations are coupled other programs like public interactions, academic sessions and various competitions inviting public participation.

• As part of scientific sessions, NOTTO has conducted many transplant programs

• In 2019, NOTTO organised the Annual Transplant Coordinators Conference along with the Indian Association for Transplant Coordinators (IATC)

• NOTTO has made optimal use of social media platforms to propagate awareness about deceased organ donation

• She learned many lessons from the global woman leaders in the field of organ donation and transplantation, including her own personal experience.

• Women donors are more in number than women recipients. Statistics show that in 2016 in the US, women accounted for 63% of the living kidney donors (women donate 1.5 times more when compared to men). The same is applicable to other countries like Europe, Canada, Brazil and South America which is a matter of concern.

• Dr. Vasanthi concluded by saying that amidst many trials and tribulations her strong determination and self-motivation have kept her going. She is also thankful to the many men who have been her constant well-wishers, supporting her career progression.
Speaker 4: Mrs. Lalitha Raghuram

- She began her professional career at the age of 21 at LV Prasad Eye Institute, Hyderabad as an Administrative Assistant to Dr. G. N. Rao and was later promoted as the Administrator of the hospital. Dr. G. N. Rao was her mentor from whom she learned the principles of ethics.

- After serving at LV Prasad Eye Institute for 7 years, she joined the Eye Bank Association of India as its Executive Director.

- She underwent technical training at the International Eye Bank in Prague, Czech Republic, where she got the opportunity to do cornea retrievals and had the privilege to get trained in slit lamp evaluation and manufacturing McCarey-Kaufman medium (MK).

- She went to Baltimore to the International Federation of Eye Bank for getting trained in the administrative aspects.

- After returning, she set up an eye bank in June 1993. Ms. Aishwarya Rai Bachchan, the winner of the Miss World 1994 pageant was approached to endorse the cause, which turned out to be a major boost for eye donation in the country.

- In that period, the hospital corneal retrieval program was initiated in hospitals to facilitate eye donation. Additionally, she was successfully able to premiere the movie ‘Schindler’s List’ in 6 cities, in aid of Eye Bank Association of India after approaching the Director of the Paramount Pictures whom she had met at an event in Mumbai.

- After her 10 years of service in the eye bank, she joined MOHAN Foundation and began her journey in the field of organ donation.

- In 2001, she started the MOHAN Foundation branch in Hyderabad. She has counseled more than 200 families for organ donation so far.

- She lost her beloved son Mr. Swamy Narayan who was declared brain dead after a car accident and she and her family members decided to donate his organs.

- Mrs. Lalitha and her husband Mr. Raghuram were awarded the CNN IBN Real Heroes Award for this brave act and walking the talk.

- She concluded her talk by saying that she is looking for more opportunities to enhance and save lives.
Session 8: My First Deceased Donation or Unique Transplantation – Perspectives from a Young Transplant Coordinator

Chairpersons: Dr. Sumana Navin and Dr. Vrishali Patil

Speaker 1: Lt. Col. Anita Nair

- Lt. Col. Anita Nair began her session by thanking NATCO and said, though she has completed 22 years of service in Military, as a Neuro Matron in Army, she only has minimal experience as a Transplant Coordinator.

- Though she was trained for the role in 2014, she independently started performing her duties as a TC in the year 2019 in Command Hospital (SC) Pune.

- She narrated her first donation experience which took place on a Sunday morning after receiving a call from the ICU. She carried with her a mixed bag of emotions that included excitement, fear of unknown and uncertainty as she dealt with every step of the process.

- Lt. Col. Nair explained how she handled the case right from assessing the deceased donor, performing apnoea test, counseling the family, broaching the topic of donation and getting consent, followed by MLC clearance, up until coordinating with ZTCC.

- She cited that the whole process was not just chaotic and strenuous, but also disorganized. She added that effective coordination with ZTCC helped accomplish the task successfully.

- She thanked ZTCC Pune for all the support accorded to her during her journey as Transplant Coordinator in Pune.

Q: Dr. Virshali Patil: What was your major learning from the first deceased donation?

A: The main lesson learned from the first deceased donation is that one has to set protocols, SOP and be well organized.
Speaker 2: Dr. Nagraj Naik

- Dr. Nagraj began by introducing himself as a Nephrologist and Transplant Physician, who is also a trained Transplant Coordinator.

- He was trained at MOHAN Foundation by Mrs. Lalitha Raghuram

- His center in Hubli is relatively new and was issued the transplant licence in September 2018. The first live kidney transplant was performed in May 2019 and cadaver registrations also began around the same time, but their first deceased donation happened on 22nd February 2020, after eight failed attempts.

- During every failed attempt he recollected the words of Mrs. Raghuram, “try and try, one day you will surely succeed” and did not get disheartened.

- He terms his first deceased donation as unique because the concept was new in his part of the state as this was the first deceased donation in Hubli-Dharwad region and moreover the donation happened after Jeevasarthakathe rolled out new protocols.

- As per the new ruling when a donation happens, all the organs would go into the general pool unlike before, when they could utilize one kidney in same hospital which was selfless in the true sense. It was also unique for them because the donor was the son of a security staff of the hospital, also pursuing his dialysis technician course in same hospital.

- He concluded his talk by saying that it was a selfless act since his institution didn’t get any organ despite all the efforts, but they were happy to save two lives.

Speaker 3: Mr. Amit Singh Chauhan

- Mr. Amit Singh began his talk by recalling the journey related to organ transplant in his institution.

- They obtained permission for retrieval and organ transplant in August 2019 and the first renal transplant was performed in December 2019 and till date their institution has performed five live renal transplants under the Ayushman Bharat Pradhan Mantri Jan ArogyaYojana (PMJAY) scheme, under which all the patients underwent free treatment.

- Among the five live renal transplants one was ABO incompatible. He added that the patients also received immunosuppression medication free of cost under the PMJAY for 6 months. They are looking forward to begin organ retrieval at their centre.
• He concluded his session by saying that he is planning a public education program on organ donation in his institution in the near future.

Session 8: Reinventing Ourselves in the New Normal

Chairpersons: Mrs. Lalitha Raghuram and Dr. Rajesh Chandwani

This session was dedicated to the memory of Mrs. Komal Pawar, who was a heart and bilateral lung transplant recipient. She was a member of TRIOMPH, the patient support group of MOHAN Foundation, and was very active through her NGO Komal New Life Foundation. Mr. Dhiraj, Mrs. Komal’s husband shared about their struggle with the illness and Mrs. Komal's tireless campaigning and dedication to the cause after her recovery. Mr. Dhiraj hopes to continue her legacy by doing his bit for the cause.

Chairperson Mrs. Lalitha Raghuram mentioned that this session will be about NGOs sharing their experience of adapting and operating during the COVID-19 pandemic.

Speaker 1: Mr. Rajeev Maikhuri – ORBO, AIIMS

Mr. Rajeev Maikhuri is a Senior Transplant Coordinator with the Organ Retrieval Banking Organisation (ORBO), AIIMS, New Delhi. He started off saying that it has been tough to reach both individuals and groups to convey the message of organ donation during the COVID times. He came up with the idea of the ‘Ride for Life’ campaign, a solo cycling initiative to spread the message. He has so far covered 5000 km, of which 700 km was in the Delhi NCR area. He was also joined by two young social work students from Madras Christian College; the campaign is open to everyone committed to the cause.

The objective of the cycle rally is to:
• Promote organ and tissue donation
• Express gratitude to the donor families
• To connect with transplant surgeons, transplant coordinators and the NGOs working for organ donation
During this period, he has also celebrated special occasions like International Daughter’s Day by visiting two families, one of which had donated the organs of their 16-year-old daughter; a tree planting initiative was also undertaken.

Mr. Maikhuri participated in the NOTTO Tweet Competition and won the Best Poster Award. A special ride organized on the 12th October was dedicated to Dadhichi Deh Dan Samiti for their exemplary work in creating awareness about organ donation. A t-shirt signing campaign where political leaders, who were involved with the Dadhichi Deh Dan Samiti pledged as organ donors, was organized as well. He has been organizing webinars where eminent speakers from the organ transplant field have participated.

Mr. Maikhuri ended his talk by thanking NATCO, Organ India, IATC, Boult Audio, the organisations who have been his constant supporters.

**Speaker 2: Ms. Sunayana Singh – ORGAN India**

Ms. Sunayana Singh, the CEO of ORGAN India spoke about how the organization has adopted an intensive campaigning format using social media platforms including Facebook, Twitter and Instagram for its awareness initiatives.

Their Facebook Live sessions featuring doctors, government officials, transplant recipients and donor families turned out to be a great success. 13 such sessions were organized between July and August with promising viewership numbers. Dr. Vasanthi Ramesh, Dr. Ravi Mohanka and Mr. AnupJalota were some distinguished speakers who were featured in these sessions.

**Speaker 3: Mr. Nilesh Mandlewala – Donate Life**

Mr. Nilesh Mandlewala, Founder & President of Donate Life talked about new learnings for promoting Organ Donation during the COVID-19 pandemic. During this pandemic they had organized various webinars related to organ donation on various topics such as: What is brain death; Organ Donation is need of the hour; Heart transplant - the last frontier: Light on flight of life; Organ Donor - the real hero; and Experience of new lease of life by a recipient.

An exclusive program on organ donation was organized for the officers and the staff of Lok Sabha Secretariat. He also added that they made optimum use of the digital platforms of Donate Life to create awareness about organ donation due to which awareness about organ donation reached millions of people across the nation and the globe.
During the COVID-19 pandemic when there was a decrease in the ratio of cadaveric organ donation in India, his NGO Donate Life was on the toes to facilitate cadaver organ donations which successfully gave new lease of life and vision to 34 persons with the donation of 12 kidneys, 6 livers, 4 lungs, 3 hearts, 1 pancreas and 10 corneas from Surat.

**Speaker 4: Mr. Rajesh Shetty – ReBirth Foundation**

ReBirth Foundation mainly focuses on creating awareness and they innovatively campaign by way of conducting short films contests based on the organ donation theme. The Green Corridor Short Film Competition has successfully completed three editions so far and the current season has received close to 170 registrations.

Ms. Arati Gokhale of ZTCC is a member of the jury which selects the winning entries.

Mrs. Komal Pawar was the Chief Guest in the season that recently concluded. She distributed cash awards to the winners.

**Speaker 5: Dr. Kulwant Gaur – Shine India Foundation**

Established in 2011 at Kota, Rajasthan, Shine India Foundation’s work focuses on eye, organ and whole body donation. Their efforts so far have resulted in 996 individuals regaining vision and 12 successful organ donations. Their work has been honored by Mr. Venkaiah Nadu, the Vice President of the country.

The Foundation has been instrumental in the Kota Medical College getting its NOTRC license.

Door-to-door awareness about whole body donation was carried out during the pandemic. A newspaper advertisement campaign to disseminate information about body donation in an attempt to bust the myths around it was also carried out. The efforts resulted in around 100 people signing up for voluntary body donation.

**Speaker 6: Mrs. Pallavi Kumar – MOHAN Foundation**

Mrs. Pallavi Kumar spoke about the ‘Mission to Reach Millions’ initiative of the Foundation that had featured live music concerts by celebrity artists from all over the country performing for the cause. Ms. Usha Uthup, Ms. Aishwarya and Ms. Saundarya, Great Granddaughters of Bharat Ratna M. S. Subbalakshmi, Warsi Brothers, artists from Shankar Mahadevan Academy were a
few artists who performed. These concerts were viewed in great numbers on social media platforms and were instrumental in raising close to Rs 15 lakhs.

Synchrony Dialogues, a series of panel discussions were kicked off in June, open to everyone interested in the topic was another noteworthy initiative. The Foundation also continued its awareness initiatives in the virtual format.

**Speaker 7: Mr. Anil Srivatsa – Gift of Life Adventure Foundation**

During one of his regular, long drives to promote the cause of organ donation, Mr. Srivatsa interacted with a large volume of people in the recent times, despite the pandemic. He also managed to counsel the family of woman suffering from a kidney ailment about the option of live donation. Unfortunately, on a drive from Chandigarh to Jalandhar he developed the COVID infection and is on his way to recovery now. He will continue his mission as soon as he becomes better.

**Speaker 8: Ms. Sreelakshmi Satyan – Quit to Care**

Ms. Sreelakshmi, a student from Kerala started Quit to Care, an initiative to spread awareness about the ill effects of smoking when she was living in the Middle East, a few years ago. She gradually began to include organ donation campaigning in her agenda which later intensified through focused awareness activities in various platforms.

The pandemic has not put a stop on her efforts. She was one of the panelists in the Igniting Young Minds discussion, part of MOHAN Foundation’s Synchrony Dialogues. She successfully organized ‘Life, Pass it On’ a virtual event for youngsters to commemorate Organ Donation Day. Poster designing, slogan writing and recorded short speeches on the theme of organ donation were part of the event organized in association with the MOHAN Foundation. Winners and participants were given certificates.
Session 10: Panel Discussion – How to Start a Skin Bank

Moderator: Ms. Pallavi Kumar

Panelists: Dr. Rajesh Powar and Dr. Somesh Balakrishnan

Why is there a need to start a skin bank in the country?

Dr. Powar: One aspect of tissue donation which has achieved less attention is skin donation. Through this, we can create a great impact on society, just like eye donation. In India, a huge number of patients are suffering from burns. Every year, in India, over 10 lakh burns accidents happen and more than 1 lakh of people succumb to injuries.

If Burns victims are surgically treated with early excision and skin grafting of the burns wounds on the third to sixth day, one can use the harvested skin, from deceased skin donors – the process which is known as allograft. This greatly reduces the morbidity, chances of victim’s death, chances of infection and many other possible complications.

It is a two-fold issue in India; we currently do not have enough specialized burn units and there is also shortage of skin from deceased organ donors.

How to increase the procurement of skin? What would work better – hospital vs. home interventions? How do we go about making sure that there is more skin available for patients in need of it?

Dr. Somesh: There are two ways through which procurement of skin from deceased organ donors can be improved in India. Firstly, there is a need to create awareness. After eyes, skin is the only tissue which can be harvested at home. This message has to be communicated clearly to the community. A lot of community work is being done to educate people about organ donation. We can tie up with existing eye banks to execute skin donation programs and create awareness. Secondly, the counselors who counsel the relatives in hospital setups need to provide proper information to the family of the potential deceased skin donor. When they inform the family that they could donate the skin of their loved one, the family thinks that the body of the deceased will be disfigured. The message from the counselors should clearly be delivered to the family, informing them of the specific areas from where skin will be harvested, and how the process would not disfigure the body of their loved one.

Normally, the practice is to harvest skin only from the hip to the ankle, both from the front and
back areas, which is then covered with a bandage. In our custom, the lower part of the body is always well covered.

During my training in Amsterdam, skin was harvested even from the back of the body and upon my return to India, I did harvest skin from the back in a couple of cases. It is important to get feedback from the donor’s relatives through the counselors, about any issues they may have. In my experience, when we harvested skin from the deceased donors’ backs, the families were not happy, because the back portion was visible during the last rites ceremony. We even try not to harvest skin from the feet, since it may be visible.

**Is this true for all skin banks across India?**

**Dr. Somesh:** No, I believe people do harvest skin from the back as well. But based on my personal experience, I do not harvest from the back.

**Dr. Powar:** We do harvest from the back, because the body of the deceased is not greatly exposed during the last rites rituals in the area we are located. The customs vary from place to place. We harvest skin from the lower back, hips, thighs and legs.

In patients who have been on anticoagulant medicines or blood thinners, there may be bleeding issues, in which a good amount of padding should fix. Most skin banks in North India and Maharashtra also harvest skin from the back.

**As of now, how many functional skin banks are there in India?**

**Dr. Powar:** In India, we have around 17 skin banks. Most of them are situated in Maharashtra, Karnataka, Tamil Nadu, Madhya Pradesh; a few in Northern India also, but not as much as in the southern side.

**How should the transplant coordinators communicate with the family of the deceased, when talking about skin donation?**

**Dr. Powar:** We need to speak to the relatives and emphasise that only the upper layer of the skin being taken; otherwise, they think that the entire skin is peeled off. It is not so, since only a thin layer of skin is harvested and hence, there is no issue of disfigurement.
What kind of infrastructure, manpower and equipment is required to set up a skin bank in India? What is involved in the process of retrieving, processing and storage?

Dr. Powar: In terms of manpower, we need to have trained professionals who can go and harvest the skin either from home or at the hospital, trained to use equipment like dermatome. Doctors, nurses and even paramedics could be trained to harvest the skin. In fact, there are places where even non-medical people including social workers form a part of the harvestingskin, under the leadership of a surgeon.

A team of 2 to 3 people should be prepared to harvest skin at home or in the hospital. We need a biotechnologist or a technician who can process the skin, once the skin is harvested, since there is a proper technique through which the skin has to be processed and stored. Facilities for processing as well as storing the skin have to be arranged for.

What is the cost of setting up a skin bank, and subsequently run it?

Dr. Somesh: Ours was the first skin bank in Tamil Nadu, set up in a small 30-bedded hospital. When we started our skin bank, both the harvesting and processing was done by us. Initially, when we started, the biggest problem was the lack of manpower to run the skin bank. In skin banks, it is not feasible to employ somebody fulltime, since all of this is voluntary work. In Chennai, we have good support from Rotary, which help us in running the skin bank.

When we think of setting up a skin bank, equipment is one of the most important requirements. The most integral equipment in a skin bank is a battery-operated dermatome, so there is no need to depend on power supply while harvesting the donor’s skin. A good dermatomemay cost 12 to 15 lakhs and is the biggest investment for a good skinbank.

It is important to start small and then go big. All you need to have is a good blood bank refrigerator, which maintains the uniform temperature of 4-degree Celsius. If your hospital has a good laboratory, then you need not investment separately for lab equipment. Investingintwo, good, battery-operated dermatomes would itself cost 30 lakhs. With all the other equipment, you would have to spend another 40 to 50 lakhs, to complete the set-up. Manpower has to be managed on a voluntary basis. It is very difficult to employ people and pay them regular salaries. Since March, I have only harvested skin from one deceased skindonor.
What is your take on manpower being voluntary?

**Dr. Powar:** We have trained paramedics in the hospital, who assist in harvesting the skin. A doctor is always accompanying the team, when the skin is being harvested. Leaving aside the COVID-19 situation, we have not encountered difficulty in harvesting skin, since ours is a teaching hospital. We have many who are being trained in plastic surgery and they are always there on duty.

Due to the COVID-19 situation, there was a lot of hesitation in teams going and harvesting skin, since the cause of death was not known and the exposure of the team to COVID-19 was a concern; that is why we had stopped harvesting temporarily. We have restarted it in the last couple of weeks and we do this in cases that are not COVID-19 positive, especially those who passed away in the hospital. For home retrievals the samples are collected and tested for COVID-19, and the harvested skin is kept aside before processing test reports rule out the infection.

**Comments/Questions:**

**As per the THOA, only the cornea can be retrieved by a trained technician and no other tissue can be retrieved by someone other than a doctor**

**Dr. Powar:** There is always a doctor present in the team. In the presence of the doctor, the skin can be harvested by the paramedic. It is not solely done by the paramedics, since they are always accompanied by the doctors.

**Ms. Pallavi:** The provision for adding technicians to retrieve cornea was added much later in the THOA, so similarly this can also be done for skin donation.

**Can a biotech person also counsel families, if trained?**

**Dr. Powar:** Yes, they can. We have a bio-technician who goes along with the team and counsels families for donating skin of their loved one. She also takes on the role of a counselor at times when the counselor is unavailable when death has occurred in the hospital.

We have a counselor who is a victim recovered from burn injuries and she has a major impact when interacting with a potential skin donor’s family; the conversion rate is pretty high when she goes to counsel.
How many burn specialists are using donated skin in India?

Dr. Powar: The skin banks also cater to centers which do not have skin bank of their own. Many plastic surgeons have started using cadaveric skin for burn victims. We have also supplied skin to places like Gujarat and Allahabad. We can cater to any part of India as long as we can manage to maintain the cold chain.

How is the skin allotted?

Dr. Somesh: We get a requisition from plastic surgeons for skin. They tell us about the depth of the burn and the area they want to cover. We mostly work around the area of 1500 to 2000 sq. cm. During skin processing, the skin will be meshed and measured and it will be kept in test tube bottles filled with glycerol, which is a preservative. Bottles are marked with the amount of skin that has been measured in them for easy reference and so can be easily distributed based on the requirement of different centers.

Does the documentation for skin donation require any special kind of training?

Dr. Somesh: The documentation is quite straightforward and simple. In our center, we have a blood bank and we follow the same administrative practices for the skin bank too.

The processing in the skin bank is done by me along with a paratechnician. We document and label every test tube and mark the sq. cm. of skin available in each test tube. At the time of issuing the skin, the blood bank staffs help us. All the details, including information about the cadaver from which the skin has been harvested, to which hospital the skin has been sent for transplantation, is made available for easy reference in the future.

Can skin harvested from a donor be directly used, or does it have to go through processing?

Dr. Somesh: If the skin is taken from someone to be used in a different part of the body of the same individual, no processing is required. However, skin harvested from a cadaver, has to be stored and processed. We have to provide skin which is sterile and easy for the plastic surgeon to use the skin while transplanting it on the recipient.
Vote of Thanks: Mrs. Arati Gokhale

The vote of thanks for the International Conference of Transplant Coordinators, 2020 was delivered by Mrs. Arati Gokhale, Central Coordinator, ZTCC Pune. She thanked the sponsors and supporting organisations – National Bioethics Conference, Tata Trusts, SBI Foundation, MOHAN Foundation, and ZTCC Pune for making the conference possible. She also extended her thanks to the Chief Guest, Dr. Farrokh Wadia, NHSBT, Women in Transplantation speakers, Executive Committee of NATCO, and all transplant coordinators who had taken part in the conference.

She also thanked Mr. Jerin Rajan, HR & Admin Executive, MOHAN Foundation for the technical support rendered. She ended her talk by mentioning that through this conference she had gained a wonderful experience of listening to faculties from different parts of the world.

Dr. Vasanthi Ramesh, Director, NOTTO in her closing remarks mentioned that, it was vital bringing together the doctors and transplant coordinators on the same platform as there is a lot they can learn from each other. The individual in the field is the right person to give you the feedback and it is the transplant coordinator who is basically the person in the field, interacting day in and day out and works 24 to 36 hours at a stretch, counseling donor families. They are the ones who can tell us what could make a difference and how potential donors can become actual donors.

On that note, a virtual group picture of all the participants and the faculties was taken and the conference came to an end with everyone departing the meeting with kind words of farewell.

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### NATCO Committee

<table>
<thead>
<tr>
<th>S. No</th>
<th>Name</th>
<th>Designation</th>
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<tbody>
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<tr>
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# List of Faculty

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<thead>
<tr>
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<td>Dr. Lori Jeanne West</td>
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</tr>
<tr>
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</tr>
<tr>
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<td>Dr. Noble Gracious</td>
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</tr>
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<tr>
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<tr>
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<tr>
<td>38</td>
<td>Dr. Rajesh Chandwani</td>
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</tr>
<tr>
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</tr>
<tr>
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<td>Dr. Sanjay Dixit</td>
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</tr>
<tr>
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<td>Ms. Sreelakshmi Satyan</td>
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<tr>
<td>47</td>
<td>Ms. Sujata Ashtekar</td>
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</tr>
<tr>
<td>48</td>
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</tr>
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<td>49</td>
<td>Dr. Sumana Navin</td>
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</tr>
<tr>
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<td>Ms. Sunayana Singh</td>
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</tr>
<tr>
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<td>Dr. Vasanthi Ramesh</td>
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<td>Dr. Vivek Kute</td>
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</tr>
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</tbody>
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