

# Network and Alliance of Transplant Coordinators

## **TOWARDS NEWER HORIZONS**

### **Proceedings of**

**14<sup>th</sup> Annual International Conference of NATCO**

**&**

**31<sup>st</sup> Annual Conference of the Indian Society of  
Organ Transplantation, ISOT 2021 Kochi**

**October 9-10 (Saturday - Sunday), 2021**

**Organised by  
Network and Alliance of Transplant Coordinator**

**Supported by**





# PROCEEDINGS

*of*

*14th Annual International Conference of NATCO*

*with*

*31st Annual Conference of the Indian Society of  
Organ Transplantation, ISOT 2021 Kochi*

*October 9 - 10, 2021*

*Virtual Conference*

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## Foreword

It gives me great pleasure to write the foreword for the proceedings of the 14th Annual International Conference for Transplant Coordinators held online on October 9-10, 2021. The conference was organized jointly by the Network and Alliance of Transplant Coordinators (NATCO), and MOHAN Foundation under the aegis of Indian Society of Organ Transplantation (ISOT) and was held with the 31st Annual Conference of the Indian Society of Organ Transplantation 2021.

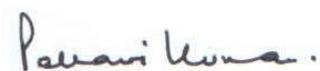
The Conference this year was aptly titled “Towards Newer Horizons” and it was an endeavour to look beyond the pandemic and enthuse the Transplant Coordinators to put renewed energies and efforts to augment organ donation and transplantation in their country. The conference covered incisive and practical topics under the following broad themes:

- Organ Donation & Transplantation during the COVID-19 Pandemic
- Paediatric Organ Donation and its Unique Challenges
- Learning from International Experiences

COVID-19 has been a great equaliser and has impacted the organ donation and transplantation program across the world. While the pandemic did not allow for a physical meeting, the online platform was a great opportunity to bring in some very experienced and renowned speakers from around the world allowing for learning from the experiences and best practices from other parts of the world. This truly enriched the discussions.

The online nature also allowed for Transplant Coordinators of many countries to attend as delegates. There was a representation of nine countries.

I am confident that the well compiled ‘Proceedings’ will become a point of reference for possible solutions in this complex field among both well-performing and emerging states that are undertaking deceased donor organ transplantation. My best wishes to everyone working to promote this heroic cause.



Ms. Pallavi Kumar  
Vice President  
NATCO

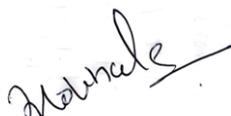
## Acknowledgement

It gives us great pleasure to bring out the proceedings of the 14th Annual International Conference of NATCO, held virtually during the 31st Annual Conference of the Indian Society of Organ Transplantation, ISOT 2021 Kochi on October 9-10, 2021.

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.

NATCO and MOHAN Foundation would like to acknowledge the support of the following organisations in making the event a success - Indian Society of Organ Transplantation (ISOT), Zonal Transplant Coordination Committee (ZTCC) Pune, SBI Foundation, and SBI Card.

We thank members of ZTCC Pune and ISOT for the arrangements during the conference. We also thank the MOHAN Foundation team comprising Dr. Hemal Kanvinde, Dr. Jimmy Gupta, Dr. Aanchal Makhija, Dr. Hansika Parwani, Dr. Sanaa Bhadwal, Mr. Atharva Bahad, Ms. Elizabeth Prassanna and Ms. Preeti Goswami for their contribution to the preparation of the proceedings.



Ms. Arati Gokhale  
President  
NATCO



Dr. Sunil Shroff  
Managing Trustee  
MOHAN Foundation

January 25, 2022

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## **Day 1 – October 9, 2021**

### **Welcome and Inauguration**

The inaugural ceremony on the 9th evening began with an invocation by Mr. Sandeepan Arya of Muskaan. Ms. Arati Gokhale, President of NATCO delivered the welcome address and Ms. Surekha Joshi presented the secretary's report. Dr. A G Huprikar (Secretary, ZTCC Pune), the Chief Guest for the occasion, appreciated the work of MOHAN Foundation and expressed his gratitude to the transplant coordinators who keep the deceased donation program going. He listed the following areas that should be focused on to improve donation rates:

- Extended criteria donors – to avoid organ wastage
- Considering possibility of multi-organ donation in all cases
- Promotion of organ donation in the public sector – encourage public-private partnerships
- Promotion of tissue donation
- Promotion of donation after cardiac death to increase donor pool
- Better coordination between SOTTOs, ROTTOs and other bodies

Dr. Vivek Kute (Secretary, ISOT) and Dr. Sunil Shroff (Managing Trustee - MOHAN Foundation) launched the new website of NATCO, congratulated the organisers and wished the conference success.

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### **Session 1: Free Paper Presentations by Transplant Coordinators**

**Judges: Dr. Sujata Rajapurkar and Mr. Raghuram Kuppuswamy**

The following nine research studies were presented:

1. Dr. Amit Joshi – Cross-sectional study on Nurses' Attitudes towards Organ Donation
2. Dr. Marzieh Latifi – The effect of acceptance and commitment therapy (ACT) on grief symptoms of organ donors' mothers
3. Dr. Omid Ghobadi – A successful solution to prevent the decline of the training effect of organ donation teams

4. Dr. Katayoun Najafizadeh – What kind of Television programmes are more effective in motivating the people to take Donor Card?
  5. Dr. Zahra Rahimi Khalifeh Kandi – What are the causes of family refusal for Organ Donation – A retrospective study
  6. Dr. Parul Gupta – Literature on Organ Transplantation Knowledge, Attitudes and Practices in India: Evidence and its Implications
  7. Ms. Sunayana Singh – Radio: The way Forward for Mass Information Dissemination on Organ Donation
  8. Ms. Jasneet Kaur – Understanding the current organ donation scenario in India - A post-COVID-19 analysis of calls received on ORGAN India's 24-hour helpline
  9. Ms. Lochana Jadhav – A comparative study on awareness level of tissue donation in Pune with special reference to corneal tissue donation and skin donation
- 

## **Session 2: Transplant Pregnancy Registry International – an Opportunity for Collaboration between TPRI, ISOT and NATCO**

**Chairperson: Dr. Ravi Mohanka**

**Speaker: Ms. Lisa A Coscia**

Ms. Coscia began her talk by playing a video featuring transplant recipients who went on to have successful pregnancies. The video included Ms. Alecia McFadden – a liver transplant recipient with 3 children and an athlete; Ms. Kanika Jain – a kidney transplant recipient and mother of a boy; Ms. Anna Fischman – a liver transplant recipient (pediatric) and mother of two, who explained how the TPRI is a treasure trove of information for recipients considering pregnancy. The video also gave an overview of TPRI which was founded in 1991 by Dr. Vincent Armenti, a transplant surgeon; Ms. Coscia and Dr. Michael Mortiz (Principal Investigator, TPRI) shared the vision of TPRI. A voluntary research study, TPRI studies the effect of pregnancy in transplant recipients and the effect of immuno-suppression drugs on pregnancies. TPRI, since its inception, has

tracked around 5000 pregnancies in both male and female recipients. Mr. Howard Nathan, CEO of Gift of Life shared how a donor's gift is what ultimately makes this circle of life a real possibility. TPRI is celebrating its 30th anniversary this year and Ms. Coscia was excited to share the commemorative video with the NATCO audience.

The first known post-transplant pregnancy occurred in a female recipient in 1958. Both the donor and recipient who were twin sisters went on to have successful pregnancies. TPRI which was earlier known as NTPR began collecting data internationally since 2016. TPRI uses a multi-pronged data collection approach involving telephonic interviews, reviewing of medical records and long-term follow-ups. India currently has one recipient who is part of TPRI, and Ms. Coscia hopes this increases in the future. Studying pregnancy outcomes by country, and comparing outcomes across countries is an exercise TPRI wishes to undertake in the future to help its patients better.

Ms. Coscia shared pregnancy outcomes in both female and male recipients, organ wise, and in case of multi-organ transplants. Maternal outcomes during and after pregnancy in kidney, liver and kidney-pancreas recipients and outcomes in new-borns in these abdominal transplants were presented. It is encouraging to see that many recipients, part of TPRI have become grandparents.

The pre-pregnancy criteria and recommendations offered by the American Society of Transplantation for recipients contemplating pregnancy were explained. Effects of the various immunosuppression drugs in pregnancy outcomes and breastfeeding (example: birth defects, miscarriages in case of MPA drugs) were explained and the importance of planned pregnancy to ensure stability of the transplant was emphasized. Outcomes in pregnancies fathered by transplant male recipients, which are almost similar to the general population, were shared as well.

Ms. Coscia shared with the audience, the various resources developed by TPRI and journal articles that are available online. In her summary, she highlighted the importance of planned pregnancy, involvement of a multidisciplinary team to manage the pregnancy, understanding that these pregnancies are high risk, and factors that influence the pregnancy and how TPRI will continue contributing and help recipients. Ms. Coscia shared the TPRI's contact information to request for resources and report pregnancies in recipients and thanked NATCO for the opportunity as she ended her talk.

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## **Session 3: Swamy Narayan Memorial Oration**

**Chairperson: Mr. Raghuram Kuppaswamy**

**Speaker: Mr. Howard Nathan**

Mr. Howard Nathan, President & CEO, Gift of Life Donor Program, USA delivered this year's Swamy Narayan Memorial Oration. He spoke about Mrs. Lalitha Raghuram who was honored by former President Dr. Abdul Kalam in 2004 for walking the talk, as she and her husband donated the organs of their son. He highlighted the mini fellowship in organ donation offered at the Gift of Life Institute, in collaboration with MOHAN Foundation. He quoted that, through organ donation one has the power to rewrite someone's story and spoke about his vision and personal connection with this noble cause.

Mr. Nathan began with an overview of organ donation and transplantation worldwide. He then spoke about the evolution of heart transplants, early regional procurement programs in the US, his journey as a transplant coordinator, how he developed a training program for transplant coordinators, the challenges and issues faced in the early OPOs, and early organ donor referral system. The NATCO 24-Alert system and its role in extrarenal organ sharing, National Organ Transplant Act (P.L. 98-507), changes affecting OPOs in the 1980s, United States waiting list, Michael Jordan Organ Donation Campaign, current US organ donation and transplant structure, 57 OPO service areas in the US, US organ donor experience, DCD and DBD (2002-2020) were also highlighted.

He then went on to explain the genesis of Gift of Life Donor Program, innovative strategies of Delaware Valley Transplant Program Philadelphia, Pennsylvania Act 102, The GOI Transplant Information Centre, driver's license registry, Donor Designation (DD) in the U.S. 2020, designated donors among recovered donors, tissue donation process, growth of DCD donors (1994-2020) and donor recognition ceremonies. He spoke about the 'Moment of Honor' - a special prayer offered to honor the deceased donors and their families and mentioned that Gift of Life Donor Program has coordinated 53,000 transplants in the US so far. He then listed a few up-and-coming innovations in donation and transplant such as:

- Ex-Vivo organ perfusion: the future
- Dr. Robert Montgomery, Director of the NYU Langone Transplant Institute receiving a heart from an HCV donor
- First pediatric hand transplant: Zion Harvey

- Uterine transplants from deceased donors

He briefed on how COVID affected the transplant program. He talked about the Gift of Life partnering with the community, the Transplant Games of America, and the living donor ceremonies. He ended his talk with a beautiful quote by UNOS, “without the organ donor there is no story, no hope, no transplant. But when there is an organ donor, life springs from death, sorrow turns to hope, and a terrible loss becomes a gift.” Mr. Raghuram Kuppuswamy thanked Mr. Nathan for the enriching talk.

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## **Session 4: Unique Partnerships with Government Department**

**Chairpersons: Ms. Bhavana Jagwani and Ms. Sunayana Singh**

**Speaker: Mr. Mahendra Soni, IAS**

**Ms. Jagwani:** What did Rajasthan specifically do to augment the Centre’s ruling regarding driving license?

**Mr. Soni:** While applying for driving license in the Sarathi software, there is a provision/field asking do you want to be an organ donor, which was optional, and one could easily skip this. Rajasthan, in September 2020, made that provision/field mandatory to answer, no one could skip that; all applicants must mark Yes or No. The option of skipping the question was removed. Since then, 2.7 lakh people have pledged to be organ donors via driving license.

People who choose Yes, have some awareness about organ donation. If the question would have just acted as a mechanical consent, everyone then would have clicked Yes; however, 75% of people said no. Therefore, it is safe to say those marking Yes via driving license, are actually consenting.

MFJCF and MOHAN Foundation’s efforts have been tremendous in making this possible. They have laid the groundwork for the provision of adding organ donor logo in driving license. Maybe in the future, forward and backward linkages will be created to unite these consents with the health department.

**Ms. Pallavi:** Around the world, there are systems in place wherein the hospital/doctors can see via driving license if the person is an organ donor or not. How can these systems be incorporated in our country?

**Mr. Soni:** Once we are on the right track to obtain consent via driving license in a sizeable number, with experts from MOHAN Foundation and MFJCF, we can have a dialogue with the government of India regarding creating a system. There will be challenges as lot of laws and issues would be involved, but once we have a strong ground level work done, we can move forward.

**Ms. Singh:** When people get their driving license, and say yes to organ donation, is some material made available to them to enhance their knowledge about organ donation, like some movie or written literature?

**Mr. Soni:** Though we don't have any movies now, we do have printed material available in the learning license training room, across all District Transport Offices in Rajasthan and at the entrance of our office also.

**Ms. Singh:** Are there currently any programs for training of RTO staff?

**Mr. Soni:** We had circulated written material regarding this across all offices, and in our regular review meetings, but we currently do not have dedicated training for the RTO staff. In future we do plan to design a structured program to make this happen. As we lose countless precious lives via road accidents every year, working on how to turn a tragedy into hope for someone else is close to my heart.

**Dr. Muneet:** As you mentioned that it is now mandatory to say yes or no while applying for driving license in Rajasthan, is it not a compulsion in other states?

**Mr. Soni:** Yes, in other states the option to skip, is offered. The applicant can choose to not exercise this option and skip the question altogether. We have removed this skip option, to ensure the applicant must answer either Yes or No. This may seem like a small change, but it has had a huge impact. Instead of skipping, now the applicants must think what to fill in.

**Ms. Singh:** Is it not a central government form?

**Mr. Soni:** Yes, the software is from central government, but certain liberties are given to state government also, and they can choose to exercise them accordingly as per state and central laws.

**Dr. Hemal:** Do people who choose Yes as an option in the form, get any link to NOTTO where they can see other details or carry a card?

**Mr. Soni:** No, currently no such system is in place. But in the future, hopefully such a system will be set up.

**Concluding remarks:**

The government in collaboration with NGOs, can build a strong system to promote organ donation across the country. The transport department is willing to provide every possible assistance required in system strengthening.

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**Day 2 – November 10, 2021****Session 1: New NGOs on the Block****Chairpersons: Dr. Muneet Kaur Sahi and Capt. V M Swamy****Speaker 1: Mr. Ranjan Singh**

Mr. Ranjan Singh spoke about his NGO, Scholars Foundation, that has been working in the field of children's education, and in the last 1 year they have initiated awareness on organ donation, called the Scholars Mission for Life. He mentioned that to begin with, his group undertook the Organ Donation Ambassador Training offered by MOHAN Foundation and then started conducting awareness events. They wish to concentrate in the medical and paramedical areas so that all brain death cases can be converted to actual donors.

He requested help in getting good speakers and faculty for the events that they plan to organize in the future.

**Speaker 2: Mr. Prasanna Karandikar**

Mr. Karandikar of The Social Reforms, a part of Trade With Jazz (TWJ) in Chiplun spoke of the genesis of the project. They initiated a needs-based survey of social causes and found that organ donation was poorly represented. They hired a scholar to undertake the work and had him undergo the MOHAN Foundation's Organ Donation Ambassador Program. After the training, the scholar, Mr. Shubham Lad has been conducting awareness in schools and colleges on organ donation. They want to concentrate on smaller villages around Chiplun for their work.

### **Speaker 3: Mr. Viresh Shah**

Mr. Shah represented Manav Jyot, a Kolkata-based NGO which has successfully coordinated 3000 cornea donations. They started working for organ donation after they joined the Bengal Organ Donation Society. Their work is focused on public education and cornea donation.

### **Speaker 4: Mr. Tejpal Singh Batra**

The I Gift Life Foundation, founded in 2016, works to promote organ donation through public awareness among students in colleges as well as staff of multinational companies. They are a member of the Zonal Transplant Coordination Centre Pune, and this has helped them to network. In the pandemic they set up a chatbot on organ donation and worked on their website. Mr. Batra mentioned that his daughter is his main motivator and the brain behind all work done.

### **Comments**

Dr. Muneet commented that all the NGOs can work together to make the public aware of the opportunity to save lives. Capt. Swamy commented that in Kolkata he is very happy to see the work of Manav Jyot and would like them to learn more from MOHAN Foundation.

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## **Session 2: Swamy Narayan Best Transplant Coordinator Award – Presentation by Nominees**

### **Judges: Dr. Rajeevalochana Parthasarathy and Mr. Raghuram Kuppuswamy**

On the second day of 14th Annual International Conference for Transplant Coordinators, nominees for Swamy Narayan Best Transplant Coordinator made their presentations.

Dr. Ashwini Chaudhary from New Era Hospital Nagpur, Ms. Mayuri Barge, Transplant Coordinator of Dr. D. Y. Patil Medical College, Hospital & Research Centre, Pune, and Ms. Prarthana Dwivedi, Transplant Coordinator of Indira Gandhi Government Medical College & Hospital, Nagpur were the nominees for Swamy Narayan Best Transplant Coordinator Award 2021.

Ms. Prarthana Dwivedi (the award winner) highlighted the impact of deceased organ donation project in Nagpur and peripheral areas. The project helped in sensitization of medical,

paramedical staff, police, and the public. Ms. Prarthana also elaborated on the impact of community awareness in neighboring states as most of the identified brain-dead patients are referred from these states. Lastly, she presented the number of organs and tissues donated thereby saving lives of organ failure patients which doubled from the beginning of the project and showcased the impact of promoting deceased organ donation in government hospitals. Ms. Prarthana also highlighted the challenges experienced and practical difficulties faced while working in a government hospital.

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## ***Organ Donation and Transplantation during COVID-19 Pandemic***

### **Session 3: Corneal Donation – getting back on track with COVID-19 Pandemic (Guidelines and Protocols)**

**Chairpersons: Dr. Kulwant Gaur and Lt Col Pioni V**

**Speaker 1: Dr. Umang Mathur**

Dr. Umang Mathur shared his views on the effects of COVID-19 in the society. The pandemic has affected everyone, and eye donations were no exception. During the first wave of COVID-19, no one was sure what was safe and unsafe because it was a novel virus. Experiences were novel and many new things were learned. The biggest concern for the health sector was to get the staff to work in a situation where deaths were happening all around. The pandemic has taught resistance to change. People need to be informed, safe, smart, and prepared to fight the pandemic.

#### **Discussions:**

##### **A) Operational Guidelines for Hospital Management during COVID-19 outbreak**

- SOPs and protocols had to be rewritten to manage the eye care hospitals
- There has been a drastic fall in transplants since the pandemic; started rising from April 2020
- There has been 10-15% shortfall in eye donations as compared to 2019
- Resuming eye bank services in COVID-19 era has become need of the hour

## **B) Key challenges in COVID-19 pandemic**

- Probability of causing transmission of SARS-COV-19 to recipients and eye bank staff
- Uncertainty existed regarding availability of donors and feasibility of tissue recovery
- There was no clarity about volume of surgeries to be expected and probable demand for tissues

## **C) Reference model of eye bank**

- Donor acquisition: Acquiring consented donors through counselling appropriate deceased patient families in hospitals or through voluntary calls. Specific regulatory documentations and medical screening of deceased for contraindication to donation are required.
- Tissue harvest and preservation: Harvesting and preserving tissues if donor acquisition is complete appropriately. Specific harvesting skills and qualified personnel are required. Pre-defined steps are executed in specific order for aseptic and surgically acceptable tissues. Instruments and consumables need to be stored, used, and disposed per protocols.
- Evaluation: Evaluating retrieved tissue and donor (serology tests, medical history review) and reject unsuitable tissues that are harvested. Specific regulatory requirements on test and documentation, and an evaluation criterion must be followed. Equipment usage and maintenance protocols are also needed.
- Tissue distribution: Matching suitable tissues to surgeon's need and deliver to surgeon. Specific documentation must be maintained and transmitted. Allocation, receipt and return protocols should be there and need based open container should also be available.

## **D) COVID-19 screening forms**

- Eye donation counsellors must fill the COVID-19 screening forms. Background information and medical history of the deceased should be filled on the first page of the form. COVID-19 screening forms must always be double checked.

## **E) Training of eye hospital/bank staff**

- One-on-one training for staff is required and SOPs must be modified.

- PPEs are mandatory for hospital staff.
- It has been observed that during the initial stages of the pandemic, eye counsellors stayed motivated. They did not want to be at home but were inspired to get back to work.

### **F) Resuming eye bank services**

Voluntary eye donations reduced since the medical history of the deceased was unclear. The hospital corneal retrieval programme has been supported because of the availability of deceased person's history.

### **G) SCEH eye bank 2021 trend**

There was a huge difference between corneas retrieved and corneas utilized, because of contraindication and guidelines. Starting September 2020, the number of corneal transplant increased. After the second wave started, eye hospitals resumed corneal retrievals and transplants as eye donation and transplant team had learned many new things and became more confident to work in the COVID-19 situation. Protocols were more clearly laid out. Utilization rate of corneas is now 85-90% as compared to 65-70% pre-COVID. This can be attributed to choosing the right candidates and adequate staff training.

### **Chairperson's Remarks**

Dr. Kulwant Gaur shared that his team had to say no for eye donations during the first wave of COVID-19 in Kota, though many people wanted to donate voluntarily. But the hospital teams continued to motivate people to fill the pledge form for eye donation, despite not doing any retrievals. Zoom and other digital platforms proved useful for training the staff and constantly motivating them.

Lt. Col. Pioni: What are the challenges that you have faced in preserving the corneal tissues during the initial stage of pandemic?

Dr. Mathur: We have different preservative mediums. In India, we use MK medium for preserving tissues that should be utilized within 72 hours. Glycerine can be a great option to preserve the tissues, especially in case of emergency.

### **Conclusion**

The SOPs must be modified and the staff trained accordingly in order to perform better than earlier. People need to be informed and updated on the new guidelines. Good experience in running eye banks has been gained during the pandemic. Based on the eye hospital's experience, the following was suggested for planned resumption of eye bank services during the pandemic:

- Exposure Risk Analysis
- Personal Protective Equipment usage training
- SOP revision and staff training on modified SOPs
- Criteria-based selection of donor sources
- Participatory planning, involving the staff and double checking at critical process junctions to manage a smooth transition

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## **Session 4: Protocol on Body Donation during COVID-19 Pandemic**

**Chairpersons: Mr. Rajeev Maikhuri and Dr. Srivari Bhanuchandra**

**Speaker: Dr. Rohini Motwani**

The objective of the session was to discuss the protocols followed in cases of body donation during the COVID-19 pandemic from a hospital's perspective and discuss the possible steps and protocols that other hospitals and medical establishments could adopt to kickstart the programme into its full working capacity.

Dr. Motwani initiated the session by stressing upon the importance of the act of voluntary body donation and its role in advancing medical research and training, with reference to the role of body donation in the COVID-specific research. The criteria for accepting body donation in the current pandemic situation was namely:

- Death due to natural causes (all ages)
- Availability of death certificate (mandatory)
- COVID-19 test negative report

Dr. Motwani highlighted several instances where body donation cannot be accepted such as, decomposed body, autopsied bodies, death due to causes like AIDS or any other unnatural causes.

### ***Decision Making***

Although the final decision lies with the hospital/institution accepting the body donation, relative and friends play an important role in the decision too.

### ***COVID-19 Pandemic: Effects on Body Donation***

Dr. Motwani discussed the cadaver shortage during the pandemic in India and all over the world, owing to the uncertainty surrounding the nature of spread of the virus which had halted all donations. After the directions from the Ministry of Health and Family Welfare on body donation protocols and management, body donations resumed. There were no body donations in the first and the second waves of the pandemic. A recent instance of body donation of a COVID positive patient in India, wherein the family donated the body, hoping to contribute to research towards COVID-19, was shared.

Dr. Motwani stressed on the need to develop strict SOPs, in-depth training of staff and recommends the use of telephone, mail etc. for the donor family to contact the hospital during the pandemic. In her end note Dr. Motwani discussed the lack of evidence pointing towards the transmission of the virus via skin of the deceased, however this mode of transmission cannot be ruled out without any concrete evidence.

### ***Successfully Running Body Donation programs***

Dr. Motwani highlighted certain aspects to be kept in mind while running a body donation programme during the pandemic:

- Safety and wellbeing of the staff
- Surface decontamination: disinfection
- Transportation of bodies

Body donation is generous Gift of Life. It is an individual's decision, supported by family and friends. Several organizations such as MOHAN Foundation work in tandem with medical institutions to support voluntary body donation, training the staff and in creating awareness.

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## Session 5: Challenges of Coordinating Donations during COVID-19 Pandemic – Sharing by Transplant Coordinators

**Chairperson: Dr. Ramdip Ray and Dr. Vipin Koushal**

**Speaker 1: Ms. Mayuri Barge**

### ***Brain Death Declaration***

In her presentation, Ms. Barge stated some of the challenges she experienced as a Transplant Coordinator in the organ donation and transplantation field during the COVID pandemic. She explained how the NOTTO guidelines were a boon to restart the program without any further disruptions.

She then shared the following statistics:

<b>Organ Donation Statistics in Maharashtra (23rd March 2020-30th September 2021)</b>		
<b>S. No</b>	<b>City</b>	<b>Donations Coordinated</b>
1	Mumbai	41
2	Pune	59
3	Aurangabad	0
4	Nagpur	12

Ms. Barge, then gave an overview of the donations that took place at D. Y. Patil Hospital, Pune in COVID scenario and mentioned that the team facilitated 13 deceased donations during that challenging time.

**Speaker 2: Mr. Gipson John**

### ***Recipient Coordination***

In his talk Mr. John covered the recipient challenges during COVID scenario in both living donor and deceased donor organ transplants. He stated that the donation numbers initially dropped when the pandemic was at its peak, but then the guidelines framed later helped in resuming the programme. The mortality and morbidity of the end-stage organ failure patients increased, turning the situation, challenging for the health care workers who had high probability of getting infected. He highlighted the key challenges related to all aspects which restricted the transplant services from functioning.

<b>Living Donor Transplants</b>	<b>Deceased Donor Transplants</b>
Strict government protocols	Patient reluctance
Safety concerns	Managing stress and anxiety
Limited resources	Increased mortality and morbidity
Logistical constraints	Logistical constraints
Documentation constraints	Financial issues
Financial crisis	Limited resources
Committee meeting challenges	Safety concerns

He also shared the following measures that he and his team practised to overcome the challenges:

- Elective transplants postponed, strict enforcement of safety protocols, careful selection of transplants in case of emergencies
- Selective usage of new and available resources, travel restrictions managed with authorization letters
- Managed meetings with minimum quorum and sometimes done online
- Strict adherence of COVID protocols, segregated wards, and ICUs for COVID and non-COVID, continuity of care in case of exposure
- Proper advance financial planning, advance deposits, crowd funding options offered

**Speaker 3: Dr. Srivari Bhanuchandra**

***Organ Allocation***

Dr. Srivari Bhanu Chandra’s presentation highlighted the following:

- During the pandemic many hospitals were converted into COVID centers and were only focusing on those cases
- Very few brain death declarations in hospital due to lack of expertise and facilities

- Lockdown meant empty roads and almost no road traffic accidents. Out of 35 deceased donations that took place during the pandemic only 2 were RTA cases and the rest due to IC bleeding or hypertension
- Increased flow of calls about medicines, plasma, oxygen concentrators, hospital beds rather than organ donation and brain death
- Family counselling for organ donation was affected due to unavailability of near relatives/ decision makers
- Registered patients and family members were not ready for transplantation during pandemic as they worried about post-transplant stay at hospital

Dr. Ray was interested in knowing how altruism and unethical practices related to organ donation have been affected by the pandemic. Dr. S K Mathur was invited to comment on the discussion and he gave a brief overview of certain challenges and how they were overcome by rolling out specific guidelines.

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## **Session 6: Owing the Deceased Organ Donation Program in COVID-19 Pandemic – A Hospital Team perspective**

**Chairpersons: Dr. S. K. Mathur and Dr. Arpita Chowdhury**

**Speaker 1: Dr. Prachee Sathe**

Leading the intensive care unit team, Dr. Sathe and her team have faced numerous challenges during the pandemic and many lessons were learned. Lack of ownership and dedication in transplant unit will lead to sluggishness and lethargy in the program.

The list of challenges faced during COVID times for organ donation was:

- Traumatic lung contusions being misidentified as GGOs on HRCT thorax and hence not admitted in the hospital to receive treatment; it was to prove they were non-COVID patients.
- 2 COVID RT-PCR tests were required as per guidelines to rule out false negatives and sometimes Bronchoscopy had to be performed to rule out COVID-19.

- In one case, family members had to travel by bus from Bihar to Mumbai as trains were not operational. Such instances cause delay in organ donation decision making and result in long donor maintenance period.
- Recipients were also not willing to take risks of any infection from BSD donors and post-transplant immunosuppression during COVID times.
- Relative crunch of skilled human resources and administrative issues due to pandemic; unavailability of skilled manpower led to many delays.
- Lack of evidence and guidelines regarding organ donation.

Dr. Sathe also highlighted the worldwide trends in transplantation reduction during the pandemic. More than 48239 waitlisted patient life years was lost during this period. The number of transplants increased after the first wave as transplant centres learned how to adapt to the new guidelines. In D Y Patil Hospital, a strict visitor's policy was introduced, making it greatly challenging for families to have contact with their loved ones and accepting death and organ donation became difficult. The RTPCR testing component was an additional burden in the transplant programme, delaying brain death certification and multiple teams worked together to smooth this out. Organ procurement proved challenging even for the most experienced doctors as recipient safety became the highest priority amid great complexity and uncertainty.

The ER, CCM, Lab, Radiology, Neurology, Transplant teams along with the management and administration had to be in coordination at all times and the social worker/coordinator had to ensure this. This model has worked successfully for Maharashtra.

Limited resources, increased complexities and heightened emotions – key components of any pandemic should not deter us as the demand for life-saving organs continues to increase. Adapting to emerging knowledge and individualization of decision making are the key aspects to focus on.

## **Speaker 2: Dr. Chinnadurai R.**

COVID-19 worsened the already existing gap between deceased donations and patients in waiting list. COVID restrictions and pandemic led all the healthcare professionals, including intensivists, away from organ donation. Many non-COVID patients lost their lives because of unavailability of ICU beds.

Despite all these challenges, Dr. Chinnadurai's team facilitated 17 organ donations. This was managed by ensuring dedicated support and care for potential donors; a team to certify brain death and nurses always being on the alert. Donor maintenance became utmost priority and exclusive grief counsellors were assigned in addition to transplant coordinators. Support from the hospital administration was greatly helpful.

Fear of COVID affected the manpower available as many staff did not turn up for work. COVID testing became hard and donations came to a complete halt following government orders. In certain instances donations were not possible due to various reasons including critical care staff being in quarantine, police being unavailable for MLC clearance and families unable to visit the hospital to provide consent.

Dr. Chinnadurai's team took the initiative to learn everything about COVID testing protocols and went as far as doing the testing themselves to ensure donations could be made possible. All precautions were taken to ensure non-COVID donors did not get infected. Regular screening of all staff part of the transplant program for infections and prompt quarantining of COVID suspected staff became routine.

### **Speaker 3: Dr. Satish Logidasan**

The Government Stanley Medical College with its team of around ten intensivists had achieved the feat of becoming the first public hospital in the country to perform a liver transplant.

One of the earliest challenges was regarding who would sign the brainstem death certificate for organ donation, as the junior doctors were apprehensive about doing that. Therefore the senior team from the hospital came forward and signed the papers for the certification and documentation which instilled confidence among others. A paper, "A decade experience in brain dead maintenance unit, 'A Stanlean Soujourn'" documenting the experience was published. The paper explained the successful donor maintenance protocol designed and adopted by Stanley Hospital. 120 organ donors were successfully maintained, and donations including paediatric ones were facilitated by the team in the last decade. The team has been actively participating in many awareness initiatives in collaboration with NGOs as well. The hospital also holds the distinction of the only government centre to have performed a bilateral hand transplant.

As the first wave of COVID hit, all the intensivists were assigned to various ICUs and donations took a hit completely. The hospital became a dedicated COVID centre and the transplant team was also burdened with treating outpatients. There was also a drastic reduction in workforce;

many team members were infected which led to work being shared and the ownership component was lost.

Different doctors handled suspected donors and 8 potential donors couldn't be converted as there was no dedicated/experienced team available for donor maintenance and brain death certification. A dedicated team taking the ownership of the transplant programme is the only way to ensure the programme's success.

### **Comments**

Chairpersons Dr. Mathur and Dr. Brar appreciated the efforts of the speakers and their teams in ensuring the donations happened even during the pandemic and encouraged everyone to not give up hope and look forward to resuming work with determination.

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## **Session 7: From Uncertainty to Newer Horizons – NGOs Speak**

**Chairperson: Dr. Ramdip Ray and Mr. Suresh Kishnani**

**Speaker 1: Ms. Sunayana Singh**

ORGAN (The Organ Receiving and Giving Network) India, an initiative of Parashar Foundation founded in 2013, conceived the Community Radio Project in 2019, which was then broadcast in Dharamshala, Gurugram, and Vidisha. During the pandemic ORGAN India has been running radio shows on all aspects of organ, tissue, and body donation in Chandigarh, Kurukshetra, Hisar, Rohtak and Ludhiana. Ms. Sunayana discussed in depth, the methodology of setting up and running a radio-based community awareness programme; she also stressed upon the great impact of the radio shows in increasing website traffic, phone calls, and donor pledges.

Ms. Sunayana introduced the online campaign run by ORGAN India in collaboration with MTV called MTV ORGANdaan in 2020 and the World Transplant Games held in 2021. She discussed the impact of the Angdaan Ek Naya Jeevan campaign held in collaboration with JK Masale in Kolkata in 2021. Ms. Sunayana concluded the session by impressing upon the audience the large-scale impact of radio-based awareness and extended help from ORGAN India to organizations who wished to enter this niche area of community radio awareness.

### **Comments**

Mr. Suresh Kishnani congratulated ORGAN India for their initiative and their efforts in the field of organ donation through the medium of community radio even during the difficult pandemic situation across the country.

### **Speaker 2: Mr. Sandeepan Arya**

Muskaan Group has been a pioneer in the field of organ donation since 2004 along with the support of Indore Society for Organ Donation. Mr. Sandeepan, while discussing the status of organ donation and transplant during the pandemic, explained the way in which Muskaan maintained continuous contact with the community and with the help of around 150 community workers extended their support towards COVID relief activities.

From his experience Mr. Sandeepan shared that the continuous awareness workshops, appreciation of donor families, support to donor families during the time of mourning etc. has helped bring organ donation to the forefront in Indore and increasing public acceptance towards organ donation. He also appreciated the support of Member of Parliament and Commissioner of Indore, and Dean of Indore Medical College for the organ donation campaign in the city.

### **Comments**

Mr. Kishnani, appreciated the efforts of the Muskaan Group to remain in constant contact with the community during the pandemic and their COVID relief initiatives. He highlighted that the support provided by the Muskaan group to the community during pandemic will make it easier for the public to approach the organization for matters related to organ donation.

### **Speaker 3: Mr. Nilesh Mandlewala**

Donate Life has been working on creating organ donation awareness and family counselling all around the clock since 2005. Mr. Mandlewala introduced the 360-degree approach to awareness adopted by Donate Life which includes use of seminars, talk shows on radio and TV, street plays, walkathons, exhibitions etc.

Mr. Mandlewala highlighted the use of webinars to promote organ donation during the pandemic and the initiative taken by the organization to promote organ donation through their YouTube channel. He shared the recent multi-organ donation of a two and a half year-old donor in Surat, the first of its kind in India and donation from two brain dead donors in Gujarat in one day, thereby

saving the lives of 12 individuals across the country, which gathered appreciation across the country.

A new initiative of Donate Life aims to appreciate and honour the family of donors through My Stamp - personalised stamps from India Post. Mr. Mandlewala ended his talk by mentioning that Donate Life has so far facilitated 949 donations till date in Gujarat which is a significant achievement.

### **Comments**

Mr. Kishnani congratulated Donate Life for their efforts in creating awareness through webinars and YouTube and the commendable work done in Surat in facilitating organ donations.

### **Speaker 4: Ms. Bhavna Jagwani**

MFJCF (MOHAN Foundation Jaipur Citizen Forum), a unit of Jaipur Citizen Forum has been working in the field of organ donation since its inception in 2013 and continued to do so during the pandemic. Ms. Bhavana Jagwani introduced an initiative of MFJCF – Angdata Smarak, India's first Organ Donor Memorial. This memorial bears the names of the organ donors of Rajasthan. She highlighted the efforts of MFJCF during the pandemic to raise funds to support installation of oxygen plants in the government hospitals.

The organ donation awareness campaigns of MFJCF shifted to online platforms, and new initiatives such as live musical programs were introduced. Ms. Bhavana spoke about MFJCF conducting regular radio programs on AIR for public awareness on organ donation, targeting the rural population in Rajasthan. A recently organised online photography contest, gained tremendous support and proved to be of great impact for public education. The awareness session conducted for GST and custom officials in Chandigarh proved greatly effective as well.

### **Comments**

Mr. Kishnani thanked Ms. Bhavana Jagwani and MFJCF for introducing and inducting him into the cause of organ donation and appreciated the Angdata Smarak initiative of MFJCF.

### **Speaker 5: Dr. Kulwant Gaur**

Dr. Kulwant Gaur from Shine Foundation explained the role of the Foundation in the promotion of eye and body donation in Kota. Dr. Gaur spoke about the importance of body donation and how

their work in Rajasthan has resulted in people from smaller towns like Bhawanimandi pledging for body donation. Based in Kota, Shine India caters to many surrounding towns as far as 170km. He mentioned that many myths, lack of knowledge, unavailability of infrastructures is what deters people from signing up for body donation.

Door-to-door campaigns, press coverage, innovative awareness creation mediums are techniques that can be used to educate people. He ended his talk by showcasing some examples of press coverage of donations facilitated by Shine India.

### **Comments**

Mr. Kishnani mentioned that he was aware of Shine India's work and Dr. Gaur's commitment, from the days when he was posted in Rajasthan. He appreciated their efforts and wished them the best.

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## **Session 8: Best Practices to Improve Donation Rates – Experience Sharing by International Experts**

**Chairpersons: Dr. Vasanthi Ramesh and Dr. Martí Manyalich**

**Speaker 1: Prof. Helen Opdam – Australia**

Prof. Opdam mentioned how Australia has evolved as multicultural nation with 25 million people speaking more than 260 languages. The country has both public and private health sectors with national funding and its health system operates with the collaboration of federal, state and territory government with varying legislations on donations. Intensive Care Units (ICUs) in Australia are run by highly trained intensivists and nurses, most of whom have formal training for working in ICU.

A national reform program to implement a best practice approach to organ donation in Australia, began in 2009. This has resulted in an increase in deceased donation rate of 122%. Due to the pandemic, the numbers however have reduced. The consent rate in Australia is 62%. To improve performance in donation, it is important to measure performance to identify areas with potential to improve, and the high and low performing regions. There should be regular feedbacks on performances to improve compliance.

## **Speaker 2: Dr. Rose Marie O. Rosete-Liquete – Philippines**

Dr. Rose Marie shared the situation and challenges related to organ donation in Philippines. In 1968, first kidney transplant was attempted and the first successful transplant took place in 1969. According to research done in Philippines, kidney disease is among the top 10 causes of mortality and there is an annual increase in new patients starting dialysis by 12-18% and approximately 400-500 transplants are done in Philippines.

Department of Health of Philippines has formed Human Organ Preservation Effort (HOPE) which acts as an organ donation office and also as an organ procurement organisation. Under HOPE many zones have been created to improve donation rates; the zones were given seed money for the promotion, however it did not work. The National Kidney and Transplant Institute (NKTi) was also established.

To overcome access issues within the country, LifePort organ transporter is being used to transport organs safely by air. They have strengthened deceased organ donation by organising advocacy programs in medical colleges, hospital trauma centres and transplant facilities. Networking with the medical association has helped as well.

## **Speaker 3: Dr. Omid Ghobadi – Iran**

Dr. Ghobadi shared the two main reasons for the shortage of transplantable organs in the world: **(a) Poor case detection:** the 3 methods of case detection are – (i) passive detection, which is based on hospital reports; (ii) administrative detection, based on review of patient information from system by coordinators; and (iii) active detection, where doctors go to the ward and assess; this method is not usually accepted in Iran, mainly due to involvement of high cost. In Iran, passive detection is used and only 50% of possible donors are reported due to lack of knowledge of brain death and spinal reflexes, bad family approach, or due to fear of family aggression and dissatisfaction of healthcare, and wrong judgment about organ viability. Because of lack of funds and lack of reporting of possible donors, a solution was designed. Specific workshops for hospitals were conducted and laws on organ donation, regulations from health ministry and instructions from President of University were explained. This however did not motivate the hospital staff and lead to increase in number of possible donors. So another program, PPDDP (Persian Possible Donor Detection Program) was launched and Inspectors (experts and middle-aged nurses from hospital) were assigned to go to the hospitals to look for possible donors and report. There are telephone donor detectors (medical students, general physicians) who follow the Inspectors,

identify all patients with GCS less than 6 and report. Due to this system there is 7 times more detection of possible donors. Half of actual donors are from brain dead cases and the rest are identified following PDPP. Comparing PPDDP with active detection, the success rate is 81% in PPDP, whereas 91% in active detection. The major difference is manpower, the former has only one person and latter has a minimum of 10 people involved.

**(b) Family Refusal:** there is a 5% family consent rate in the 94 coverage hospitals. Iran, therefore has established a social awareness centre and has trained the hospital teams. They detected the main reasons for family refusal, hold weekly meetings to resolve negative opinions and develop new techniques. They also published world's first book on dealing with brain dead donor families called "85 techniques." Iranian new model for educating families and taking family consent - PIEP(Persian Interviewers Education Program) was launched. They trained the interviewers/counsellors under this program with a motto (no approach to the family is much better than approach by an inappropriate person). Because of this the family consent rate is now 96.3% in 115 coverage hospitals.

#### **Speaker 4: Mr. Abdel-Hadi Abu-Jeish – Qatar**

First kidney transplant was done in 1986 in Qatar. Currently the donor registry has 463000 people, which is 25% of adult population of Qatar.

Over the last 8 years, there has been great improvement in deceased donation pathway but Qatar is still struggling to achieve higher rates of consent. Challenges faced are: non-compliance and poor understanding among staff - 7% of nurses and doctors do not believe in brain death. To target this group, annual education courses were started, champions in ICU were assigned and TPM courses were started as well. Intensivists were included in donor management and all policies were revised and unified.

Other challenge was difficulties in family approach which included, communication difficulty and uncontrolled environment. Biggest challenges lies when families are outside Doha, causing delays because of telephone network issues, and inability to directly provide emotional support. Other factors include lack of awareness, language barriers, lack of identification of callers, natural disasters, lack of trust, and sometimes extended family members influencing the decision making.

Actions taken to overcome such difficulties were:

- Find an educated, close relative in Doha or abroad

- Intensivist breaks the bad news and then it is reconfirmed by the coordinator to improve the understanding for families
  - More time is given to families for grieving
  - Organ recipients are made to speak to the families
  - To break language barriers, medical staff of same language should be used and proper time for approaching the families outside Doha must be chosen
  - Optimal use of the donor registry to tap potential donors
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## **Session 9: Panel Discussion: Directed Donation – Is the Donor the Owner?**

**Moderator: Dr. Avnish Seth**

**Panelists: Dr. Anil Kumar, Dr. Subash Gupta, Dr. Sanjay Nagral, Dr. Sudeep Naidu, and Dr. Richard A Demme**

**Background:** Dr. Avnish Seth shared his experience of a unique case coordinated by the Fortis team in March 2020. A 48-year-old lady had sudden loss of consciousness and was placed on the ventilator. In the first apnea test, it was found that there was an irreversible loss of brain stem function. The family was approached by the hospital for organ donation. The family agreed for donation, provided one of the kidneys was allotted to the brother of the patient who was on dialysis and wait-listed with NOTTO for a kidney transplant. This would be a case of Directed Deceased Donation (DDD).

There was another case of DDD in Mumbai in September 2016 where a lawyer was allowed to jump the waitlist to receive the kidney of his brain dead brother. NOTTO allowed an ailing man to get a kidney from his brain dead brother on humanitarian grounds which was a landmark decision.

The following questions were posed to the panelists:

- Does our law allow for DDD?
- What are the ethical considerations in DDD?
- Have we faced similar situations in the country?

- How does DDD differ from conditional donation?
- Is DDD permitted in other countries?
- What should our response be to DDD situations in India?

### **Discussions:**

**Question:** Does the law in India allow DDD? What does our Transplant Act say about it?

**Dr. Anil Kumar:** As far as the law is concerned, it does not mention anything regarding DDD, because the allocation system is defined only in the rules, and not in the law. So, there is a need for a network to be established under which the organ allocation criteria can be state-specific, and can be defined by the state government in consultation with SOTTO. However, we have the national body, NOTTO which defines the direction in which the allocation should be done. The law promotes local utilization of the organs. First, we have to allocate organs within the state, then allocate to other regions. There is a geographical priority for local utilization of the organs.

**Question:** What are your views on DDD? What are the pros and cons of DDD according to you?

**Dr. Sanjay Nagral:** In DDD cases, we should first ask the family of the deceased, if it is a wish or pre-condition to donate organs? Every DDD case is unique. For example, in the Mumbai case mentioned, the potential recipient was also the one to give consent for his brother's donation.

In the Indian context, we are in a situation where everything we do is directed in some sense. Families with organ failure patients are aware of the organ shortage and the long waiting period. We should take a high moral ground when a request is made by a family to get one of the kidneys or any specific organ of their relative. A family's request should be looked at sympathetically.

**Question:** Do you think we should accede to DDD requests in our country, across the board or should there be some pre-conditions?

**Dr. Subash Gupta:** Most of living related donations in our country are directed donations. There is an authorization committee which deals with it. We could take a common sense approach to directed donation requests which are few and far between at the moment. One must remember that even if there is a directed donation for one organ, there would be non-directed donation for

many other organs. Every case has to be assessed individually, rather than the law turning it down completely.

**Question:** Do you think we should restrict DDD in some way by allowing only the near relatives to get the directed organ and also if they are already registered with NOTTO, waiting for an organ? Do you think these two prerequisites should be mandatory in our country?

**Dr. Sudeep Naidu:** We need to draw a line; do we restrict allocation of the deceased person's organs to his/her first-degree relatives or friends and colleagues. We already have the legislation in place for living related donors. There are screening and authorization committees, so the same set of rules can be applied for deceased directed donation. The question in DDD is who is the legal owner of the body; would a living will matter? When alive, an individual has the right to donate their organs to whomever they want in a living donation situation; but upon death, the body becomes a state property. The societal needs have to be met and a sympathetic approach should be taken in a DDD case provided all the pre-conditions are met and the recipient is already registered for the waiting list. There should be no coercion or monetary benefit.

**Question:** Is DDD allowed in other countries in the world?

**Dr. Richard A Demme:** DDD is allowed in USA but it is not publicized or promoted. It is still uncommon. Though it is mentioned in the law, people are unaware of this, including donors. DDDs are highly uncommon in the US because it is unlikely that the family is aware of a patient and also the blood/tissue compatibility matters. DDDs however cannot be directed to a specific group of people, example race or religion as this would make it conditional donation.

### **Discussion Summary:**

- Any potential recipient must be listed with NOTTO. There should not be a last minute listing of the recipient. All types of donation should be encouraged as long as the organs are saving lives of other people given the organ scarcity.
- In India, we have a bigger issue of patient travelling to an organ. We need to change this attitude. The patient should not travel to the organ but the organ should travel to the patient.
- A conditional donation which is directed by religion or caste must be discouraged. Transferring potential donors vs utilizing NTORCs is an area that needs to be looked at.

Private organ recipient hospitals are mostly at advantage and are hence constantly pushing for donations.

- In Gujarat, all cadaveric donations are conditional donations. The donated organs have to be allocated only to a domicile person. The states are allowed to have their own allocation policy and are legally allowed to do so.
  - DDD should justify the medical need of the recipient to whom it is directed. So, initially we should follow a case-to-case basis approach as such requests are few.
  - The panelists recommended being open to DDD and formation of a committee making a decision for every individual case.
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## ***Pediatric Donations and its Challenges***

### **Session 10: Challenges of Counselling in Pediatric Donations**

**Chairpersons: Ms. Rohini Sahasrabudhe and Ms. Sujata Ashtekar**

**Speaker: Dr. Joe Brierley**

Pediatric organ donation has always been a specialty niche area. There are fundamental differences in how it operates across geographies. In the UK, the Organ Donation Task Force was set up in 2008 and it laid out protocols for all hospitals to improve the organ donation rates which proved to be successful. However, there was no mention of pediatric donation at all and Dr. Brierley during his time with the National Organ Donation Committee between 2013 and 2019 was the first to focus on the subject and introduce a pediatric national subcommittee. He also published a paper regarding pediatric donations in the UK, leading to massive improvements in the area.

The key step was to make organ donation a routine part of end-of-life care in the PICU and standard protocols have been issued to all hospitals, recognized by all national bodies. It has clearly defined the criteria for a child deceased donor; a child who is 0-18 years who has had a catastrophic brain injury due to trauma or hypoxia and the death, neurological or circulatory is verified. Donations following circulatory death have gained momentum in the UK. Only after elective withdrawal of life saving treatments in children, they are declared dead in case of DCD;

this must be standard across all PICUs.

Counseling is the most important aspect of organ donation. Education: teaching and training are key to develop best practices in this area. Organ donation training packages including approaching families and the standardized national guidelines are available online and it has improved public acceptance and confidence in the system.

The role of the coroner in pediatric donation is slightly different as compared to adult donations. Donations involving traumatic head injuries, or any suspicion involved are complicated, and it is difficult for the parents to give consent. Organ retrieval can be a coronial postmortem.

International comparison data with respect to pediatric donations is unavailable. The average in the UK is 1-2 donations per year in every pediatric ICU, widely varying between units despite the standard guidelines. In UK, on an average, there are 40-50 pediatric organ donations per year and around 3700 child, and 2100 neonate deaths. No neonatal donations were happening until 2014. Many deaths are due to complex diseases, or because of traumas which do not allow for stabilizing the child for retrieval, thereby rendering donations impossible. There are total of 28 PICUs in the UK and death verification and organ donation can be done in all these units.

The challenges would be, the fewer number of pediatric donors and even fewer of the appropriate size, leaving children at a double disadvantage. Liver and lungs – cut downs from adult donations, hearts from young brain-dead adults, and kidneys of living adult relatives are the biggest source for pediatric transplants; there are no living child donations in the UK. However, more children are donating to adults as there are more adults on the waiting list. For brain-dead pediatric donors, the protocols are standard; there are however certain ethical dilemmas with respect to DCD. A few years ago, parents were refusing to consent for donation if the organs of their child were being allocated to adults, and not to other children.

Dr. Brierley then explained the protocol to be followed for both DBD and DCD once it has been identified for a potential pediatric donor. UK's pediatric DBD and DCD donation data and reasons for unsuccessful donations, family refusal were shared. He shared with the audience links to some papers which he recommends that everyone should read.

### **Questions:**

Q: What should be the gap between the two apnea tests in case of pediatric donors?

A: A gap of 72 hours is recommended to be on the safer side; a set of 2 doctors do the testing in the UK. Testing of infants below the age of 2 months has been rare.

Dr. Bala Ramachandran commented that he agreed with Dr. Brierley's observations and hopes that DCD becomes more national in India.

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## **Session 11: My Experience with Pediatric Donation – Invited Case Discussion by Transplant Coordinators**

**Chairpersons: Dr. Bala Ramachandran, Mrs. Vrinda Pusalkar and Mrs. Surekha Joshi**

**Speaker 1: Ms. Rajinder Kaur**

### ***Case Study 1***

A 12-year-old boy fell from his mother's vehicle while returning from school and sustained a head injury. He was admitted to a private hospital in Shimla and was referred to PGI Chandigarh. Despite the efforts of the ICU team, he could not be revived and was declared brain dead. Since he was an only child, the mother was in utter shock and guilt. The ICU team contacted the transplant coordinator for counselling the parents. Poor prognosis and brain death were explained to the parents, but they were unwilling to accept, hoping for a miracle.

On the fourth day they accepted the prognosis and the next day counselling for organ donation was initiated. Later that day they gave verbal consent for the donation but were unwilling to sign the consent forms. They kept insisting to move ahead with organ retrieval without signing the consent form, as they were not in a state to sign the consent form. On the sixth day both the parents signed the consent form and both kidneys, corneas, liver, and pancreas were retrieved.

### ***Case Study 2***

A 13-year-old boy in Shimla was diagnosed with abscess and raised ICP. He was admitted in the neurosurgery ICU of PGIMER, Chandigarh. Despite the efforts of doctors, he could not be revived and was declared brain dead.

Poor prognosis and brain death were explained to the family members by the treating physicians. As the parents were both doctors, they were able to grasp the concept of brain death. Both the

parents accepted the condition of their child and possibility of organ donation was discussed with them. The grandparents however, wanted a third set of brain death testing before making the final decision.

After the third test they insisted on talking to the committee members and after discussion, family gave consent for organ donation. Both kidneys, corneas, and liver were retrieved.

### **Case Study 3**

A 11-month-old boy sustained a head injury after falling from bed. On the day of the incident, the boy was sleeping on the bed, while his mother was engaged in household chores. He woke up and tried to get down from bed which resulted in a fall, and he was lying on the floor unconscious before the mother found him. He was then taken to the Civil Hospital from where the family was referred to PGIMER, Chandigarh.

Despite the efforts of the doctors, he could not be saved and was declared brain death. The parents accepted the prognosis but opted for LAMA (Leave Against Medical Advice). Since it is mandatory in PGIMER to inform transplant coordinator about every brain death, a call was made by the team. The patient's attendants had already completed the discharge formalities, but the transplant coordinator still met with the family members and counselled them.

As the family already accepted brain death, the concept of organ donation was introduced to them. The boy's father was a regular blood donor and he agreed to donate organs of his son. He was re-admitted to the ICU, brain death committee informed, and he was declared brain dead. Both kidneys were retrieved.

### **Comments**

Dr. Bala Ramachandran: Each case had its own challenges. In the first case the parents were unwilling to sign the consent form, which often happens. They think that by signing the form they are giving permission to kill the child. It often happens when someone is withdrawing care for their relative also. In the second case, the grandparents just wanted to be extra sure, and though it holds no legal validity, it means a lot to the family.

### **Speaker 2: Mrs. Sucheta Desai**

A family from Australia, while travelling to the higher altitude areas of India noticed that their 4.5-year-old boy was complaining of headaches. They assumed it was because of the altitude

sickness and gave him some medication. When they landed in Mumbai, the boy collapsed and was immediately taken to the hospital. After several sets of tests, he was declared brain dead.

The family was informed about brain death and prognosis, and they remained calm throughout. They were then counselled for organ donation. The boy's sister told, she was taught about organ donation at her school, and wanted to do it. To this the mother replied, she too knows about it, but did not expect that it would be this early. The family agreed for donation and the boy's heart was donated to a 4.5-year-old girl in that same hospital.

Following the donation, on Valentine's Day, the family organized an event with their religious leader, in a mission church, where the donor's sister urged the crowd to pledge for organ donation by mentioning how her mother donated her brother's organ, and that he is alive in someone else.

### **Comments**

Dr. Bala Ramachandran: The key takeaway from this case is that support from family and religious leaders play a key role in convincing families to consent for organ donation. When a donor family promotes organ donation it makes a huge impact.

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## **Session 12: Caveats in the Psychological Evaluation of Face Transplant Candidates**

**Chairpersons: Dr. Amit Joshi, Dr. Sunil Keshwani and Col. R Venkat Narayanan**

**Speaker: Dr. Kathy Coffman**

Dr. Coffman began by thanking the organisers and shared a brief overview about her work in a burns unit earlier which helped her work with face trauma patients. Using case studies of her patients, she explained that face transplant is one of last resorts and is meant for restoring functions of the facial organs. Face transplant is not advised for improving appearances.

The hospital psychologist needs to evaluate the stage of grief of the patient, whether avoidance/camouflage is a coping mechanism. The patient's and their family's reaction to injury and how they are coping with the trauma is also an aspect a counsellor needs to be aware of. She mentioned that some of the trauma victims are survivors of suicide attempts and a counsellor should be aware that the patient may attempt it again.

Most patients have loss of speech, loss of vision as well as cognitive issues. Head injuries could lead to brain trauma and multiple plastic surgeries are a huge burden on the mental state of the patient. There is always a danger that patients may be addicted to opiates and cannabis for pain, some may become alcoholics. So therapy would include life skills training, physiotherapy as well as psychotherapy.

Following the face transplant, patients seem to age faster and this is quite visible in their faces. Rejection is also a major risk and supportive surgeries are mostly required. A counsellor needs to evaluate both the patient as well as the family, since their support is crucial to the recovery of the patients and in their acceptance of the new face.

### ***Discussions***

Dr. Keswani complemented Dr. Coffman on highlighting certain key points. He said that India has only now progressed to transplant of upper limbs and it would take time before attempts on face transplant can be made.

To a question regarding face transplant registries across the world, Dr. Coffman responded that only 40-50 face transplants have been performed so far in the world, and she is unaware of any registry even in France or Italy. A question was raised about counselling of patients who choose not to undergo face transplants, and Dr. Coffman replied that many patients, including veterans do not want a transplant owing to fear of rejection and the lifelong drugs required.

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### **Valedictory and Awards**

Mrs. Lalitha Raghuram – Country Director of MOHAN Foundation and Former President of NATCO opened the valedictory event on the 9<sup>th</sup> evening with a prayer. She welcomed the Chief Guest Ms. Manjula Kalyanasundaram, Managing Director & CEO of SBI Foundation and thanked her for the support. Ms. Kalyanasundaram acknowledged the efforts of the organisers and appreciated the determination and commitment of the transplant coordinators.

Ms. Prarthana Dwivedi of Indira Gandhi Govt. Medical College Hospital, Nagpur bagged the Swamy Narayan Best Transplant Coordinator Award. The winners of the free paper presentation were:

- Dr. Omid Ghobadi: A successful solution to prevent the decline of the training effect of organ donation teams
- Dr. Marzieh Latifi: The effect of acceptance and commitment therapy (ACT) on grief symptoms of organ donors' mothers
- Ms. Sunayana Singh: Radio – The way Forward for Mass Information Dissemination on Organ Donation

Ms. Kalyanasundaram announced the winners and congratulated them. Vice President of NATCO, Ms. Pallavi Kumar and President Ms. Arati Gokhale thanked everyone, requested the audience to use the NATCO website and other resources and work to increase the membership of the organisation.

Dr. Hemal Kanvide (NATCO Member, South Zone) delivered the formal vote of thanks with the recital of a Tagore's poem. The conference came to close with a group picture being clicked and attendees departing with hope of meeting each other soon.

## NATCO Committee

<b>S. No</b>	<b>Name</b>	<b>Designation</b>
1	Ms. Arati Gokhale	President
2	Ms. Pallavi Kumar	Vice President
3	Ms. Jaya Jairam	Secretary
4	Ms. Surekha Joshi	Joint Secretary
5	Mr. Siva Shankar T S	Treasurer
6	Dr. Hemal Kanvinde	Member (South Zone)
7	Dr. Bhanu Chandra Dharani Pal	Member (South Zone)
8	Ms. Bhavna Jagwani	Member (North Zone)
9	Dr. Muneet Kaur Sahi	Member (North Zone)
10	Ms. Mayuri Barge	Member (West Zone)
11	Ms. Vrinda Pusalkar	Member (West Zone)
12	Ms. Priyanka Borah	Member (East Zone)
13	Lt. Col. Pioni V	Member (East Zone)
14	Mr. Ahsaan Ullah Ansari	Member (Central Zone)
15	Dr. Amit Joshi	Member (Central Zone)

## List of Faculty

S. No.	Faculty	Affiliation
1	Dr. A. G. Huprikar	Secretary, ZTCC Pune
2	Dr. Vivek Kute	Secretary, Indian Society of Organ Transplantation & Professor – Nephrology, IKDRC-ITS Ahmedabad
3	Dr. Sunil Shroff	Managing Trustee – MOHAN Foundation, Chennai
4	Ms. Arati Gokhale	President, NATCO; Central Coordinator – ZTCC, Pune
5	Mrs. Surekha Joshi	Joint Secretary, NATCO
6	Dr. Sujata Rajapurkar	Medical Social Worker & Transplant Coordinator, Muljibhai Patel Society for Research in Nephro-Urology, Nadiad (Former)
7	Ms. Lisa A. Coscia	Senior Registry Research Coordinator, Transplant Pregnancy Registry International (TPRI)
8	Dr. Ravi Mohanka	Head, Liver Transplants Global Hospitals, Mumbai
9	Mr. Howard Nathan	President & CEO, Gift of Life Donor Program, USA
10	Mr. Raghuram Kuppaswamy	MOHAN Foundation, Hyderabad
11	Mr. Mahendra Soni IAS	Special Secretary & Transport Commissioner, Govt. of Rajasthan, Jaipur
12	Mr. Tushar C. Doshi IPS	DCP & Principal, Police Training School, Mumbai
13	Ms. Bhavna Jagwani	Convenor, MFJCF Jaipur
14	Ms. Sunayana Singh	CEO, ORGAN India
15	Mr. Ranjan Singh	Scholars Foundation, Udaipur
16	Mr. Prassana Karandikar	TWJ The Social Reforms, Chiplun

17	Mr. Viresh Shah	Manav Jyot, Kolkata
18	Mr. Tejpal Singh Batra	I Gift Life Foundation, Pune
19	Dr. Muneet Kaur Sahi	Programme Manager, MOHAN Foundation, Delhi NCR
20	Capt. V. M. Swamy	President, Bengal Organ Donation Society
21	Dr. Rajesh Chandwani	Chairperson, CMHS, IIM, Ahmedabad
22	Dr. Rajeevalochana Parthasarthy	Nephrologist, The Madras Medical Mission, Chennai
23	Dr. Umang Mathur	Executive Director, Dr. Shroff's Charity Eye Hospital, New Delhi
24	Dr. Kulwant Gaur	Founder, Shine India Foundation, Kota
25	Lt. Col. Pioni V	Critical Care Nurse & Administrator, 151 Base Hospital, Guwahati
26	Dr. Rohini Motwani	Associate Professor – Department of Anatomy, AIIMS, Hyderabad
27	Mr. Rajeev Maikhuri	MSSO & Senior Transplant Coordinator – ORBO, AIIMS, New Delhi
28	Dr. S. Bhanuchandra	Transplant Coordinator, Telangana Govt. Hospitals
29	Ms. Mayuri Barge	Transplant Coordinator, D. Y. Patil Hospital, Pune
30	Mr. Gipson John	Transplant Coordinator, Aster Hospital, Bengaluru
31	Dr. Vipin Koushal	Nodal Officer – ROTTO, Chandigarh
32	Dr. Ramdip Ray	Chief of Division of Liver Transplant – Apollo Gleneagles Hospitals, Kolkata
33	Dr. Prachee Sathe	Prof. Department of Critical Care Medicine – Dr. DY Patil Medical College Hospital and Research Centre, Pune
34	Dr. Chinnadurai R	Lead Intensivist – Aster RV Hospital, Bengaluru

35	Dr. Satish Logidasan	Associate Prof, Anaesthesiology and Critical Care, Govt. Vellore Medical College
36	Dr. S. K. Mathur	Senior Consultant Surgeon, HPB Surgery & Liver Transplantation; President, ZTCC Mumbai
37	Dr. Sukhbir Brar	Nodal Officer, SOTTO, Rohtak, Haryana
38	Dr. Arpita Chowdhury	Joint Director, ROTTO, West Bengal
39	Mr. Sandeepan Arya	Muskaan, Indore
40	Mr. Nilesh Mandlewala	Founder and President, Donate Life, Surat
41	Mr. Suresh Kishnani IRS	Chief Commissioner, Customs, GST and Central Excise, Visakhapatnam
42	Prof. Helen Opdam	National Medical Director, Organ and Tissue Authority, Canberra, Australia
43	Dr. Rose Marie O. Rosete-Liquete	Executive Director, National Kidney and Transplant Institute, Quezon City, Philippines
44	Dr. Omid Ghobadi	Deputy Director, Iranian Society of Organ Donation, Tehran, Iran
45	Mr. Abdel-Hadi Abu- Jeish	Sr. Clinical Organ Transplant Coordinator, Qatar Center for Organ Transplantation, Qatar
46	Dr. Vasanthi Ramesh	Ex. Director NOTTO, New Delhi
47	Dr. Martí Manyalich	President of TPM, Spain
48	Dr. Avnish Seth	Director, Fortis Organ Retrieval & Transplant (FORT), New Delhi
49	Dr. Anil Kumar	Additional Deputy Director General, Government of India, Ministry of Health and Family Welfare, Directorate General of Health Services
50	Dr. Subash Gupta	Chairman - Max Centre for Liver & Biliary Sciences, Max Hospital, Saket, New Delhi
51	Dr. Sanjay Nagral	Co-Chair, Declaration of Istanbul Custodian Group and Hepatobiliary Surgeon, Jaslok Hospital, Mumbai

52	Dr. (Surgeon Rear Admiral) C. Sudeep Naidu	Addl Director General Medical Services (Navy) Armed Forces Medical College, Pune
53	Dr. Richard A Demme	Prof. Dept. of Medical Humanities and Bioethics, University of Rochester Medical Centre, USA
54	Dr. Joe Brierley	Consultant Paediatric Intensivist & Director of Bioethics & Clinical Lead for Organ Donation Great Ormond St Children's Hospital, London, UK
55	Ms. Rohini Sahasrabudhe	HOD Transplant Coordination Administrator, Renal Unit, King Edward Memorial Hospital, Pune
56	Ms. Sujata Ashtekar	Consultant, SOTTO-ROTTTO, Maharashtra
57	Ms. Rajinder Kaur	Transplant Coordinator, PGIMER, Chandigarh
58	Mrs. Sucheta Desai	Former Transplant Coordinator, Mumbai
59	Dr. Bala Ramachandran	Head of the Department, Pediatric Intensive Care, Kanchi Kamakoti Childs Trust Hospital, Chennai
60	Ms. Vrinda Pusalkar	Assistant Manager-MSW at Jehangir Teaching Institutes, Jehangir Hospital, Pune
61	Ms. Surekha Joshi	H.O.D. Medical Social Work Department & Transplant Coordinator, Ruby Hall Clinic, Pune
62	Dr. Katy Coffman	Department of Psychiatry and Psychology Transplantation Centre, Cleveland Clinic Main Campus, Cleveland USA
63	Col. R. Venkat Narayanan	HOD Plastic Surgery Department, Armed Forces Medical College, Pune
64	Dr. Sunil Keswani	Director, National Burns Centre, Airoli, Navi Mumbai
65	Dr. Amit Joshi	Officer on Special Duty at Bombay Hospital & Medical Research Centre, Indore







# Network and Alliance of Transplant Coordinators

NATCO - Network and Alliance of Transplant Coordinators is a registered society with the vision to improve the professional careers of Transplant Coordinators and promote ethical organ donation and transplantation in India

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Network and Alliance of Transplant Coordinators

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