

# NAVIGATING CHANGE

## Advanced Transplant Coordinators Workshop

### PROCEEDINGS

Supported by



Organised by



March 22, 2024  
Courtyard by Marriot, Gurugram, India



## **Acknowledgement**

It gives us great pleasure to bring out the proceedings of the 8<sup>th</sup> Advanced Transplant Coordinator Workshop. The conference with the theme of “Navigating Change” was held on March 22, 2024 at Courtyard Marriot, Gurgaon. Supported by SBI Foundation, the event featured 40 delegates and 21 speakers across four sessions, fostering insightful discussions and networking opportunities.

The scientific committee comprising of Mrs.Lalitha Raghuram, Ms.Pallavi Kumar, Dr.Muneet Kaur Sahi and Dr.Hemal Kanvinde put together a good agenda and we thank the speakers and the chairpersons for sharing their thoughts and experiences in the sessions. The workshop was also supported by National Alliance of Transplant Coordinators. We appreciate their support.

The proceedings were put together by a team comprising of Ms Arshiya Fathima and Dr Hemal Kanvinde.



**Dr. Sunil Shroff**  
**Managing Trustee**  
**MOHAN Foundation**

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**NAVIGATING CHANGE**  
 Advanced Transplant Coordinator Workshop  
 March 22, 2024, Courtyard Marriott, Gurgaon

TIME	TOPIC	SPEAKER	CHAIRPERSONS
12.00 -1.00 PM	Ethical issues in donation & transplantation – Case Discussion	Dr Sanjay Nagral	Ms Dhvani Mehta Ms Priti Jain
1.00 -2.00 PM	<b>LUNCH</b>		
<b>2.00 -3.00 - Pediatric transplantation – Challenges and Way forward</b>			
	Overview on pediatric transplantation in India	Dr Sonal Asthana	Dr Vipul Gautam Ms Mayuri Barge
	Counseling for parents and children: Anxiety Denial and acceptance	Dr Vikram Kumar, Max	
	Sharing by Transplant Coordinators	K V Shweta, Aster Trilly Mathew, Maringo Asia	
<b>3.00 – 4.00 PM - Living Donation (other than near relatives) - Challenges &amp; Way forward</b>			
	Overview	Dr Anil Aggarwal	Ms Arati Gokhale Ms Pallavi Kumar
	Case sharing & Discussion	Panelists: - Mr Sanjay Jain, - Dr Amit Joshi, - Dr Arun Agrawal - Ms Latha Kumaraswamy	
<b>4.00 -4.15 PM TEA</b>			
<b>4.15 – 5.30 PM Expanding the donor pool – NTORCs</b>			
	Present status & protocols and barriers – 20 mins	Ms Lalitha Raghuram	
	Evolution of NTORCs in Vadodara and their challenges	Dr Deepali Tewari	
	Lessons learned from Kerala	Dr Noble Gracious	
	Panel Discussion	Ms Lija Mol Dr Noble Gracious Dr Deepali Tewari	Moderated by: Lalitha Raghuram

## **Day 1: Friday, March 22, 2024 at Courtyard Marriot, Gurgaon**

### **Welcome**

The workshop began with an introduction and welcome by Ms Pallavi Kumar, Director MOHAN Foundation Delhi NCR. She welcomed all the delegates and the faculty and explained that this was workshop for senior transplant coordinators and was by invite only.

She said that MOHAN Foundation in partnership with NATCO (Network and Alliance of Transplant Coordinators) organized an Advanced Transplant Coordinators Workshop titled "Navigating Change" bringing together senior transplant coordinators and NGO representatives to address critical issues in the field.

The theme of navigating change resonated deeply in our current landscape, where rapid advancements in medical science, evolving ethical considerations, and the ever-changing dynamics of healthcare systems present both opportunities and challenges. The workshop shall serve as a platform to navigate these changes collaboratively, leveraging collective expertise and experiences to drive meaningful progress.

### **12.00 to 1.00 PM Ethical issues in donation & transplantation – Case Discussion**

**Chairpersons** – Ms. Dhvani Mehta & Ms. Priti Jain

#### **Speaker –**

Dr. Sanjay Nagral, Senior consultant & Director, Department of Surgical Gastroenterology at Jaslok Hospital, and co-chair of the Declaration of Istanbul Custodian Group

The objective of the session was defining the Ethics in Transplantation and Indian challenges and their unique way of transplantation.

Dr. Sanjay Nagral said that since this group of delegates are seniors and have many years of experience, they are aware of the that ethics does not equate to law. His experience in various fora such as ZTCC Policy working group, editor at IJME, DICG has brought to him a regional and global view of ethics.

He emphasized that ethics is a social contract focused on the theme of morals, right, justice and equity. The gap between the need for organs and the availability make the situation a fertile ground for unethical practices to flourish through coercion and inducements in living donor transplantation.

In the area of deceased organ donation, a high degree of trust in the in the altruism of the family, that it is for public good and equitable organ allocation systems is expected to be in place. Challenges in the Asian countries is the ground level truths of society, bias of class, caste and gender and the domination of private sector hospitals in transplantation.

The role of the transplant coordinator is limited to counseling and ensuring all processes are

according to the law of the country. Their opinions are rarely taken for any ethical consideration in a transplant care.

With this introduction Dr.Nagrul highlighted 3-cases with ethical challenges.

1. Living related transplant where the spouse of the donor raises objection to the donation
2. Donor family requests all fees to be waived after they have given consent to deceased donation
3. How a TC can raise issues of manipulations in patient waiting lists in hospitals.

All the cases were discussed by the transplant coordinators. Points of financial and non-financial incentives to deceased donor families, role of authorities in transplant sectors, support system for transplant coordinators were elaborated upon, Refusal of spouse can affect the decision of wife for donation was discussed.

## **2.00 to 3.00 PM**

### **Pediatric transplantation - challenges and way forward**

Chairpersons - Dr. Vipul Gautam & Ms. Mayuri Barge

Speakers –

Dr. Sonal Asthana, Lead Consultant, HPB Surgery and Multiorgan Transplant, Aster CMI Hospital, Bengaluru

Dr. Vikram Kumar, Pediatric Gastroenterology and Hepatology , Centre for Liver and Biliary Sciences, Max Hospital , New Delhi

K. V Shweta, Liver Care Coordinator, Aster CMI Hospital, Bengaluru

### **The objective of the session was pediatric transplantation and the challenges faced during the counseling for parents and children's**

Dr. Sonal Asthana gave a short overview on pediatric transplant in India. He said that 10% of all liver transplants are among children, with a 75% survival rate at 20 years. He said that it is very rewarding to see result of the transplant, since there is challenge in the long horizon of growth for a child.

He informed the transplant coordinators that the Liver Transplant society has data of 600 patients in the past 10 years. Though costs may be relatively lower for a pediatric transplant, yet it is difficult to manage for most young families and so the CSR funding gains importance. He also mentioned that using a 3D printed donor liver greatly helps in planning for a pediatric transplant.

Dr. Vikram Kumar, spoke on different aspects of parental counselling. He said that parents come with their own issues of irritability, stress, anxiety, depression and guilt when they come for their first consultation. All the skills of counseling are required during this time.

The parents need to be educated about the disease, all treatment options and life post-transplant need to be explained preferably in their vernacular language. Soft words and relaxed manner and giving a lot of time for parents during consultation, checking if they have understood the diagnosis and treatment plan aids in decision making about their child. The treating doctor has to be a facilitator to the transplant and not as an inhibitor.

Ms K.V Shweta shared her thoughts on current challenges faced in pediatric transplantation. The most important need is to deal with anxiety, denial and acceptance stages of parents and extended family during their child transplantation. If the child is less than 1 year, motivation for the surgery is very low among the family. Children are malnourished and there is very little time to get them well enough for a transplant surgery, so expensive supplements are given to them. Another aspect is the affording the expensive post-transplant medicines for the child patient.

Discussion after these talks was on what government schemes and utilizing CSR funds for child transplants , NGOs's crowd funding .

### **3.00 to 4.00 PM**

#### **Living Donation (Other than near relatives) - Challenges & way forward**

**Chairpersons - Ms. Arati Gokhale, Dr. Avnish Seth, Ms. Pallavi Kumar**

**Speaker –**

Dr. Anil Aggarwal Director, Gi Surgery & Liver Transplant, G B Pant Hospital

Dr. Amit Joshi, Vice President NATCO

Panelists – Mr. Sanjay Jain, Dr. Arun Agrawal, Dr. Amit Joshi, Dr. Anil Agarwal and Ms. Latha Kumaraswamy

**The objective of the session is challenges faced by transplant coordinators and authorization committees in approvals for donations in the category of other than near relatives.**

Dr. Anil Agarwal spoke of his experience in an authorization committee. He explained how it works with the aim of saving the life of an organ failure patient. The committee basically checks that all procedures were followed correctly and all legal documents are in order. The committee also looks into any evidence of coercion or inducement for the donor.

Dr. Amit Joshi placed a case for the audience in which the authorisation committee's decision was overruled by a State High court. He said the court cannot make a decision for the committee, it can only ask for reconsideration of the first decision.

This was followed by a discussion by the panel.

- The need to educate the judiciary of transplant laws and rules and the state authorities roles and responsibilities.



- Consent from donor and donor dependents as well as spouse – it is legal or more of a social need
- Safety of living donor and organ failure patient is paramount in the decision of the committee.
- How families are primed and trained before they come for the interview and face the authorization.

#### **4.15 to 5.30 PM**

#### **Expanding the donor pool – Non- Transplant Organ Retrieval Centers (NTORC)**

Speaker –

Ms. Lalitha Raghuram, Country Director, MOHAN Foundation

Dr. Deepali Tewari, Additional Chief Medical Superintendent, Western Railways, Vadodara

Dr. Noble Gracious, Executive Director Kerala State Organ & Tissue Transplant Organisation (KNOS) & Associate Professor, Government Medical College, Thiruvananthapuram

Panelist – Ms. Lija Mol, Dr. Deepali Tewari Dr. Noble Gracious, Dr Pooja Nagpal

Moderator – Ms. Lalitha Raghuram

#### **The objective of the session is how to involve NTORC to improve donation rate**

Ms. Lalitha Raghuram explained the genesis of the NTORC (Non- Transplant Organ Retrieval Centers) and its inclusion in the Transplant Law of India. She mentioned the core conclusions of a discussion on the status and future of NTORC in Karnataka – a meeting held at IIM Bangalore. She highlighted the legal, protocol and financial issues in NTORC during a deceased donation. Dealing with donor families and training transplant coordinators for the purpose of NTORC was also discussed.

Dr. Deepali Tewari highlighted the good work done by NTORCs in Vadodara, 28 in number with 72 donations in past 9 years. Positive publicity of this work has resulted in families coming forward to donation after a death of their loved one. However, she also put forward that counseling tenets should be known whom to speak, where to speak and when to speak. And specially trained counselors can be deputed to NTORC as and when a case is identified.

Dr. Noble Gracious gave a brief description of the initial years of the KNOS which was led by many donations through NTORC. He said in his experience timely reimbursement of expenses to the NTORC and making grief counselors available to such centers is key to their success and continued cooperation. Such support need a planned financial layout from the SOTTO.

Ms Lija Mol explained the need to have an executable plan for NTORC. A simple system of reimbursement, availability of trained transplant coordinators or counselors and a point of contact for any issues during a donation can help to raise the number of donors.

The discussion was on registering all district and taluk hospitals as NTORC. Improving the skills of intensivists and neurologists to identify and certify brain death. Highlights the

successfully working NTORC systems to other SOTTOs for adoption in their states.

The workshop ended with a Vote of Thanks delivered by Ms Pallavi Kumar.






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