# INDIAN SOCIETY OF ORGAN TRANSPLANTATION MIDTERM MEETING



# PROCEEDINGS

# ASIAN PERSPECTIVES ON ORGAN DONATION & TRANSPLANTATION

16<sup>th</sup> - 18<sup>th</sup> March 2017, The Park, Chennai

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# Nafas Visual Art Festival







The first visual arts festival on the topic of Organ Donation held by Iranian Society of Organ Donation with Iranian Artists' Forum was held on August 2016.

More than 2700 artworks were received which consisted of 897 graphic art, 781 paintings, 361 sculptures, 330 photographs, 166 cartoons, and 239 illustrations.

Selected artworks from this innovative and breathtaking festival will be exhibited at the ISOT midterm meeting at The Park, Chennai.



Iran has made tremendous progress in deceaseddonor organ transplants. The transplant team at Shiraz began performing more deceased-donor kidney and liver transplants and became a successful deceased-donor organ transplant model in the country.

In 2011 and 2012, Iran was ahead of all country members of the Middle East Society for Organ Transplantation in performing deceased-donor kidney and liver transplants.

**1** st

## Asian Perspectives on Organ Donation and Transplantation

Midterm meeting of Indian Society of Organ Transplantation

and

4th Consultative Meeting of Transplant Coordinators

Proceedings

16th to 18th March 2017, Chennai

## Title

Proceedings of the Midterm Meeting of Indian Society of Organ Transplantation on Asian Perspectives on Organ Donation and Transplantation

## **Edited By**

Ms. Jaya Jairam & Dr. Hemal Kanvinde

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## Acknowledgement

27 April 2017

It gives us great pleasure to bring out the proceedings of the Midterm meeting of Indian Society Of Organ Transplantation (ISOT) - AsianPerspectives on Organ Donation & Transplantation.

We had more than 200 delegates and faculty. For the first time a meeting with Asian perspective was held in Chennai. We acknowledge the inputs of the scientific committee members of our society for developing the scientific sessions. We would like to thank the leads for the round table discussions for their planning and mobilising the members to come up with guidelines. We thank the speakers and the chairpersons for sharing their thoughts and experiences during the meeting. Special thanks to the overseas faculty who took time out from their work to attend the meeting.

ISOT is grateful to the Iranian Society for Organ Donation for bringing their Nafas Visual Art Exhibition to display in India at this meeting.

We thank the MOHAN Foundation team comprising of Jaya Jairam, Hemal Kanvinde, Aanchal Agarwal, Mareena Thomas and Sridivya for preparation of this proceedings.

Best wishes

milima

Dr. Georgi Abraham Chairman

Dr. Sunil Shroff Organizing Secretary

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## Midterm meeting of Indian Society of Organ Transplantation (ISOT) and 4th Consultative Meeting of Transplant Coordinators

## 16th to 18th March 2017, Chennai

The theme of the meeting was Asian Perspectives on Organ Donation & Transplantation.

Asia lags behind the rest of the world in the field of organ donation and transplantation compared to America and Europe. Asia does 4 to 5 per million live and deceased donor kidney transplants compared to 27 in Europe and 46 in USA, although 60% of the world population lives in this large continent.

In this meeting we discussed the best of Asian perspectives from leading countries in this field with participants from various countries that included - China, Iran, Nepal, Bangladesh, Sri Lanka, India and also from Australia.

#### Highlights of the event -

- 1. We had an exhibition of Iran's Nafas Visual Art Festival on Organ Donation courtesy of Ms. Mona, curator and Dr. Katayoun Najafizadeh, Director, Iranian Society of Organ Donation.
- 2. Robotic assisted kidney transplant for reduced scar was demonstrated with a video by Dr. Anant Kumar.
- The idea of "Creating an Asia forum for Deceased Donation & Transplantation" was supported by Ms. Wenshi Jiang, Dr. Katayoun Najafizadeh, Dr. Niroshan Seneviratne, Prof. Dr. Vimal Bhandari, Dr. Sunil Shroff, Dr. Georgi Abraham at this meeting.
- 4. Dr. Rajeev Kumar, AIIMS, conducted a workshop on IMRAD and explained the correct techniques to publish in scientific journals.
- 5. How does China perform Organ Donation without a Brain Death law? It was a very informative session by Ms. Wenshi Jiang which included new concepts followed in China such as the DBCD system of Organ Donation.
- 6. The development of central data collection system at NOTTO to research post transplantation outcomes.
- 7. We had major brainstorming sessions on Transplant Tourism, Directed Donation, Swap Donation, long term effect of Organ Donation on live donors.
- 8. Presentations on the requirement for "Uniform declaration of death".
- 9. Dr. Rezvi Sheriff, Father of Organ Transplantation in Sri Lanka discussed the need of a law to curb living unrelated donor transplants in Sri Lanka.
- 10. There was a round table discussion to propose guidelines on various medical and management issues that affect the transplant field.

## 16 March 2017, Day 1 – Morning Session

#### Inauguration

The meeting started with an Inauguration of the Advanced Transplant Coordinators' Workshop –  $4^{th}$ Consultative Meeting on Body and Organ Donation by Mr. S. V. Venkatesan and his daughter Prof. Aparna Venkatesan in memory of Mrs. Malathi Venkatesan, a trustee of MOHAN Foundation. They released the  $49^{th}$  issue of the Indian Transplant Newsletter and the Proceedings of the 'Advanced Transplant Coordinators' Workshop –  $3^{rd}$  Consultative Meeting to Improve Organ and Tissue Donation' held in 2016. The theme of this meeting was 'Gift Hope Gift Life'.

#### **Visual Art Exhibition**

In another section of the venue, there was an exhibition of Visual Arts based on the theme of organ donation. Thirty one exhibits were brought to India courtesy the Iranian Society of Organ Donation. The exhibition was jointly inaugurated by Prof. Vimal Bhandari and Dr. Katayoun Najafizadeh.

#### **Technical Sessions**

## **Body Donation in India- The Law and socio-cultural aspects in different parts of the country** Speaker- **Dr. Vaishaly Bharambe**

Chairpersons- Dr. Sudha Seshayyan & Dr. Sumana Navin

Dr. Vaishaly started with an explanation of the definition, use and need of body donations. She mentioned that though the ideal condition would be 10 students to a body, but in reality it is more than 40 students to a cadaver in most medical colleges. This is because the public is unaware of the difference between body donation and organ donation. So the only solution to this is to promote Cadaveric Body Donation.

She elaborated on the law on Body donation and its salient features. Laws governing body donation-Bombay Act no XI.....1949

Amended in 1950, 1956, 1957, 1959, 1960, 1976, 2000 and 2014 & now called as The Maharashtra Anatomy Act

Odisha Anatomy Act (2013); Delhi Anatomy Act; Haryana Anatomy Act; UP Anatomy Act; Himachal Pradesh Anatomy Act; Goa Anatomy Act and the Karnataka Anatomy Act.

Some anatomy acts allow body donation as well as tissue donation. Maharashtra Anatomy Act allows Body Donation where body is used for-

- 1. Therapeutic purposes
- 2. Medical purposes

#### Socio-cultural perspective & Body donation- Procedures in Sri Lanka

Speaker: **Dr. Niroshan Seneviratne** Chairpersons: **Dr. Sudha Seshayyan & Dr. Sumana Navin** 

Dr. Niroshan introduced the audience to the multi ethnic, multi cultural and multi religious society of Sri Lanka. He said that 70% of the country are Sinhalese Buddhists, 10% are Hindu. Both these religions support Organ Donation as people want to do good at the time of death.

About 5% of Sri Lankans follow Islam, and they have misgivings about organ donation. They believe that

- 1. One should keep the dead body whole.
- 2. They generally prefer to wait for a divine cure.
- 3. They believe if the heart is beating then person is not dead as heart is the most important factor to determine life according to them.

Dr. Niroshan touched upon the cultural beliefs and misconceptions that hinder body donation. He elaborated on how to overcome these cultural, social and religious barriers.

- 1. Start educating the young generation.
- 2. Involve religious leaders and motivate them to reach their respective religious community and clear the misconceptions of people telling them that their religion permits body and organ donation.
- 3. Opinion makers aka Influential people in the society could also be involved.

## How does China do Organ Donation from Deceased with no law recognizing Brain Death

#### Speaker: Ms. Wenshi Jiang

#### Chairpersons: Mrs. Arati Gokhale and Mrs. Lalitha Raghuram

Ms. Wenshi started with explaining a survey carried out to understand the people's perception of Organ Donation in China. Results were: Good- 10%; Bad 60% and I have no idea about it 30%. Conducting this survey helped the government to understand that the people of China don't have awareness about Organ Donation.

She listed chronologically the steps taken by the government-

- Rampant Organ trading
- Then China became a signatory of Istanbul Declaration
- Transplant tourism banned
- However demand is high
- OD by prisoners was legal
- In 2007, a pilot program to promote deceased donation was introduced
- In 2013, this was adopted as the national program

She said that in the past 7 years (2010-2017) there were 9988 cadavers who became organ donors. This way over 28000 transplants were carried out. In 2016, 4080 deceased donations were done, even though there is no law to declare brain death. 40% of the cases are Donation after Brain death and Circulatory Death (DBCD). This was possible due to dedication & determination of the Government. There is a belief that OD should not be the reason for promoting BD. She explained the protocols followed for DBCD in the hospitals.

Countries like Sri Lanka, India & sometimes Singapore are sources of organ via black market from poor people. Even Chinese people are not accepting the organ donation and take time to give consent. They need to give time to their loved one to die. They are not ready to accept the concept of Organ Donation. Family consent is very important for getting organs from the brain death patients. Red Cross Coordinators and OPD Coordinators will counsel the family members to donate organs. She was glad internationally China is getting recognised for its effort for ethical organ donation and transplantation.

#### Approaching a family for Organ Donation – The Science behind it

#### Speaker: Dr. Omid Ghobadi

#### Chairpersons: Ms. Arati Gokhale & Ms. Lalitha Raghuram

Dr. Ghobadi gave a brief introduction to the state of organ donation in Iran in the past, the problems and the solutions attempted to overcome the low rate of donation. Iran began engaging the public with celebrity engagement, events bringing donor families & recipients, active participation of the Authorities in events and convincing Religious Leaders. Through these concerted efforts, the Family Consent Rates improved from 5% in 2005 to 22% in 2010. Post 2010 TPM training was conducted. Then consent rates improved even more because of the training in 2010: 32% and in 2011: 66%

Counselors have to detect main problems of the family / reason of refusal. Same time they have to design practical solutions for the families. Dr. Ghobadi summarised the efforts of the transplant coordinators to motivate the family as -

- ✓ Building big trust between interviewer and Family
- ✓ Explaining about Brain Death
- ✓ Benefits of organs
- ✓ Taking the family consent

He said that in their training the coordinators are taught to -

- Step 1: Build Trust, Gather patient data
- Step 2: Provide space appropriately
- Step 3: Give news of death clearly
- Step 4: Acute Reaction (immediately after breaking the bad news)
  - Anger / denial
  - Do not show any reaction just be reassuring and listen
  - Short affirmation & console without physical touch
  - The they will start asking logical questions at this point share facts and information with them and you can make physical touch

Step 5: Acceptance of death by the family. If family cannot accept death, do not approach for OD. In Iran, there are 6 trained nurses for all over Iran's 115 hospitals. He described the PIEP – Persian Interviewers Education Program that trains Transplant Coordinators.

#### Panel Discussion – Creating an Asia Forum for Deceased Donation & Transplantation Panelists: Ms. Wenshi Jiang, Dr. Katayoun Najafizadeh, Dr. Niroshan Seneviratne, Dr. Rishi Kumar Kafle & Dr. Vimal Bandari Moderator: Dr. Sunil Shroff

Dr. Shroff: Do we need an Asia Forum to push Deceased OD program?

#### Dr. Wenshi:

- o Yes. Cultural values of Asian countries are different as compared to that in western countries
- We should start by sharing data

#### Dr. Katayoun Najafizadeh:

- An automatic system should be in place which is not person specific i.e. dependent on motivation and drive of specific persons in the program
- This is why western countries are doing well. There is a predefined system
- We should take the system from the West and fit it in Asia keeping in mind the culture, religion etc

#### Prof. Bhandari:

- Forum is needed
- Possibly literacy rate in India being lower is leading to our OD rates being lower
- Rural penetration is poor
- Time has come to unite

#### Dr. Niroshan Seneviratne:

- Main challenge in SL is that Asian culture is such that entire family participates in decision making Vs individual decision by western people
- BD is not diagnosed at the appropriate time
- These must come into law

#### Dr. Rishi Kumar Kafle:

- $\circ~$  Lack of awareness
- Even medical community is not aware

#### Dr. Katayoun Najafizadeh:

- Many a times, late BD referral results in loss of a potential donor.
- Audits should be in place to analyse BD reporting & BD case analysis (After this was implemented in Iran, 70 cases / month rose to 470 cases / month)
- We should meet regularly say half yearly or Annually

#### Dr. Shroff:

- Have a website that shares resource materials for Asian countries
- Have an exchange program for Asian Doctors & Transplant coordinators

## 16 March 2017, Day 1 Afternoon Session

#### IMRAD –The nuts and bolts of scientific communication & Impact Factor of Indian Journals

Speaker: Dr. Rajeev Kumar

Chairpersons: Dr. Anil Kumar, Dr. Edwin Fernando and Dr. N. Gopalakrishnan

Dr. Rajeev gave a systematic talk on what, how, why and when of writing an article. While writing a journal think of the following -

- Have something to say?
- Why are you writing?
- Keep it as short as possible but keep it complete

Structure of a journal

- I Introduction Why did you start?
- M Methods What did you do?
- R Results What did you find?
- A And
- D Discussion What does it mean?
- Conclusion

He explained the need for simple and concise introduction, the first and last sentence concept and PICO (Population, Intervention, Comparator, Outcome) – for methods. He highlighted the dos and don'ts for results and discussion. He emphasised that the scientific communication should be concise and interesting. He then introduced the concept of impact factor in journals and how to identify fraud journals.

#### Role of Data in Organ Donation

## Speaker: **Ms. Wenshi Jiang** Chairpersons: **Dr. Anil Kumar, Dr. Edwin Fernando and Dr. N. Gopalakrishnan**

She started with a numbers game which gave the atmosphere a lightness specially post lunch. She then described the five data systems used in China since 2013.

- 1. Organ Donation System
- 2. Organ Procurement & Allocation System
- 3. Organ Transplant System
- 4. Scientific Registries System
- 5. Donation & Transplant Regulatory System

She explained how the public mistrust in organ donation was overcome by the organ allocation through a computerised system which was made mandatory in all hospitals. Major policy decisions promoted the families to donate organs in Chennai. Though the country has shown leaps in rate of organ donation, they do have more than 300,000 patients on dialysis, and an annual addition of 64,000 patients.

#### **Role of Statistics in Research**

#### Speaker: **Mr. John Michael Raj** Chairpersons: **Dr. Anil Kumar, Dr. Edwin Fernando and Dr. N. Gopalakrishnan**

Mr. John explained the value of adding a statistician to any study right at the beginning. He explained how a study can be designed efficiently and the analysis done correctly in a study that has inputs from the statistician. He gave examples of research studies to highlight these points.

#### Workshop on Scientific Writing

#### Conducted by - Dr. Rajeev Kumar Assisted by Dr. Ravi Mohanka, Dr. Sumana Navin, Dr. Sanjeev Nair & Dr. Rajeevlochana Parthasarathy

This workshop involved 4 groups. Dr. Rajeev Kumar summarised a study and every group was given the work to develop the Introduction, Methods, Results & Conclusions respectively based on the given scientific study.

The groups had 60 minutes to discuss the best way to write their part. At the end the outputs developed by each team were discussed and suggestions shared. It was an extremely interactive session and the four mentors assisted the group. Dr. Rajeev also showed what he had written for the same study. This session was appreciated by all.

#### Good, Bad and the Ugly of Organ Donation on Social Media

#### Speaker: Ms. Mareena Thomas

Chairpersons: Ms. Sunayana Singh & Ms. Aneka Paul

Ms. Mareena gave a comprehensive account of the many social media sites such as Twitter, Facebook, Snapchat, WhatsApp, etc.

She enumerated the Good as -

- 1. Social Media can help us spread awareness about Organ Donation to large masses.
- 2. It can help promote a generous cause and spread real live stories of organ donors and recipients.

3. It can be used to spread the word across large populations in very less time and thus save lives. And the Bad as -

- 1. People trade organs through Social Media pages on Facebook and websites.
- 2. People advertise the buying and selling of organs.

Even though organ donation can save so many lives, it's seen as a wrong deed due to the use of social media for trading of organs. She highlighted her points using examples.

#### **Transplant Tourism**

#### Speaker: **Dr. Anil Kumar** Chairpersons: **Dr. R. Jayaganesh & Dr. V. Balaraman**

Dr Anil Kumar explained the process of Transplant Tourism, visa, availability of quality treatment in India that helps us to get patients here for transplants. India has more incoming foreigners than outgoing patients for Transplant tourism. He said that the main factors for the rise of tourism are high quality treatment at low cost; availability of world class hospital infrastructure and trained expert doctors; advanced technology and equipment; system of accredited hospitals. On the other hand he said that there were problems due to Transplant Tourism such as -

- 1. Organ buying and selling.
- 2. Patients return to their home land, so follow up after transplant is rare.
- 3. Poor transplant procedures followed in some places to hide the transplant from legal authorities when it's done illegally.

He mentioned that the Hotspots of Transplant Tourism in the world include Sri Lanka, India and Singapore. Countries like Philippines, China, Pakistan, Egypt, Moldova are top exporters of organ donors. Though there is a strict legal provision to deal with Transplant Tourism such as requirement of Medical Visa rather than Tourist Visa for undergoing any medical treatment in a foreign land, there is still violation of laws and trafficking and exports continue.

- Each year 5-10% of transplanted kidneys are through organ trade
- India is signatory of Istanbul Declaration, 2008
- No of patients coming to India for transplant –

	KIDNEY		LIVER	
Year	Total	Foreigners	Total	Foreigners
		-		-
2012	1214	-	361	-
2015	1801	467	523	264

#### Difficult Donations – Homicide, Suicide, Pregnancy

#### Speakers: Ms. Arati Gokhale, Dr. Bhanu Chandra, Mr. Johnson Alphonse Chairpersons: Dr. B. Subbarao, Dr. R. Jayaganesh & Dr. Sunil Shroff

Various Case studies were discussed involving difficult donations some of which were successful and some were not. Ms. Arati Gokhale of ZTCC Pune, representing Maharashtra explained a case of assault on a man wherein the family agreed, since the wife was pregnant in third trimester, then family was hesitant to talk to her about donation. Finally after 2 hours she also agreed to the donation.

Mr. Johnson of Apollo Chennai gave his experience of a young pregnant lady who became brain dead after an accident. The husband had given consent for donation. Patient had brain stem dysfunction.

However the fetus was alive and active. Obstetrician opinion was obtained. Doctors felt the fetus should be given first priority and patient to be maintained till the fetus reaches viable stage for C- section. He said the entire hospital came together to save the fetus. After a few days the fetus died and hysterectomy and evacuation of the non-viable fetus was performed. 1<sup>st</sup> Brain death declaration was done and it was positive. A few hours later the donor suffered a cardiac arrest. Donation did not happen. This was an emotionally draining coordination. The husband sent a Facebook post about his experience and urged everyone to wear protective gear while driving.

Dr. Bhanu Chandra gave a few examples of assault and suicide cases that were extremely tasking in terms of time management and police verification and police FIRs etc. At the end of a successful donation he wondered about the condition of the donor family. He said that specially in cases of young married female donor, there are more complications with the law and the threads of family bonding that are still getting firmed up are broken and there is lot of tension between the husband and wife's family. This leads to difficulties in consent and handling over the body after donation.

The Chairpersons discussed the cases, gave their experiences and complimented the transplant coordinators for their work.

## Implementation of the Transplantation of Human Organs (Amendment) Act, 2011 & Rules 2014 - Panel Discussion

Panellist: **Prof. Vimal Bhandari, Dr. Anil Kumar, Mr. C. E. Karunakaran** Moderator – **Mr. P. W. C. Davidar** 

Mr. P.W.C. Davidar, a senior IAS officer who has been instrumental in the development of Deceased Organ Donation in Tamil Nadu moderated the discussion on the Law on Organ Donation. In his introduction, he explained the importance of stakeholders meetings held prior to finalising the Government Orders and the need to always discuss the progress in program with frequent meetings. He made two points:

- NOTTO should be overall body and not involved in day to day working (with specific reference to NOTTO being the allocating body for Delhi NCR regions)
- National Registry should not be handled by AIIMS since AIIMS is an interested party. It should be handled by an independent body such as NOTTO

#### Responses -

Mr. C. E. Karunakaran:

• SOTTOs should come together and make suggestions to NOTTO for bringing about improvements

Prof. Vimal Bhandari:

• Advisory committee must be set up comprising chiefs of ROTTO and the other important stakeholders

Mr. Davidar:

- Stressed on consultative approach being the need of the hour
- National registry probably lacked a consultative approach
- TN's waiting list works as per seniority on the waiting list and in case of critical cases, once in a while, the queue may be jumped however that hospital has to give up its next turn
- Whenever there are conflicts in the above system in TN, they are transparently discussed & sorted
- Other states work on illness criteria

Dr. Anil Kumar:

- Regarding consultative approach not having been taken open to reviewing the laws
- Can be put up to ROTTOs for review

Mr. P.W.C. Davidar thanked the panellists for sharing their views.

## **16<sup>th</sup> March 2017**



## 16<sup>th</sup> March 2017



#### 17 March 2017, Day 2 – Morning Session

#### **Use of Art as a tool for public awareness for OD** *Speakers:* **Ms. Mona Najafizadeh and Dr. Katayoun Najafizadeh** *Chairpersons:* **Ms. Mallika Madhavan and Dr. N. Muthulatha**

Dr. Katayoun started the session with an introduction about the Iranian Society of Organ Donation (ISOD) and it activities associated with transplants. The society was formed to be able to deal with the inability to conduct cultural or social activities in the hospital that could promote awareness on organ donation among the public. The society has 20 committees divided among scientific, cultural and artistic and social work. All the three departments discuss on what needs to be contributing ideas in their specialized area. Thus, contributing into a confluence of art and medical science to create more awareness among the public. One of the programs started under this was the one=eight posts on the social media platform of Instagram.

From there on Ms. Mona Najafizadeh, Curator of the Nafas Visual Art Festival explained the cultural and art committee's initiative of visual arts festival in 2016 under the guidance of ISOD. The culmination of this was the first Nafas (means breath) Visual Art Festival held in 2016 with the motive to promote the cause of organ donation. It attempted to create a positive picture of organ donation among the public and instill a thought that organ donation is a very holy thing to do. To explain it further a movie about the same was shown that showcased the art exhibition at visual arts festival across six divisions i.e. painting, graphics, cartoon, sculpturing, illustration and photography. Mona further shared the future to establish an international festival. 31 artworks were chosen to be displayed for the workshop in India.

#### **Chairperson's Input:**

Ms. Mallika congratulated them for the tremendous response the festival got from skilled artisans. She wanted to know how ISOD was able to involve celebrities in the field of art and also manage to get such a positive response from the public. Dr. Katayoun answered that they were able to garner support from the media to announce the festival. With a MoU with municipal corporations they were able to put billboards and posters in different parts of the city. This resulted in 3000 entries, which were judged by 433 eminent artists.

Ms. Mallika added that different concepts incorporating art and the cause of organ donation was heart touching and that art is a powerful image that serves more purpose than just hanging on the wall. If we are able to make art an experiential element it would be able to bring about a lot of change, thus helping us to promote the cause of organ donation. We should be able to show people how holy organ donation is and how lives can be changed through organ donation.

## Iran – Deceased Donation model – current status and impact on live unrelated transplantation

#### Speakers: **Dr. Katayoun Najafizadeh**

Chairpersons: Dr. Nitin Kekre, Dr. Narayan Prasad & Dr. Ashish Sharma

Dr. Katayoun explained how Iran has developed a positive attitude towards organ donation. She mentioned that in 2005 the country was Ranked 42 in the world. Post 2005, they made major changes like: Volunteer projects, donor cards were introduced, Religious Leaders were taken on board and a push for more public awareness. This was followed by TPM Training, introduction of Inspector project, Train nurses to just look for BD (GCS ~ 4/5), Don't wait for physicians to inform BD, Hospital Coordinators put in place – Team for BD detection who would work in coordination. Now Iran is ranked 31 among countries that have a deceased donor program.

Dr. Katayoun and her team tried different interventions to increase the donation rates in Iran. In response to this 'fatwa' issued by religious leaders were used. One of the most important change makers was Persian Possible Donor Detection Project that was designed and started in 2009. In the program they combined three worldwide methods of detection (passive, active and administration) with a new approach and three subdivisions: Inspector Project (IP), Telephone Donor Detection Program (TDDP) and Hospital Report. Nurses and few other para medical staff were trained as Inspectors. Repeated rounds by IP and TDDP were made to keep a tab of any potential brain dead donor. This resulted in detection rate going up by 7 times more.

Persian Interviewer Education Program (PIEP) was another program where they added 40 different techniques of family approach to the accepted worldwide method according to their specific culture and religion. This resulted in increasing the family consent rate from 5% in 2006 to 96.3% in 2013.

Parliament act and cabinet law legislations also helped in setting up a better system of certifying brain death. Ministry of Health regulation in 2004 regarding living donor gave a better structure for the same.

In addition to the interventions mentioned above other programs like Iranian Network of Organ Procurement and Transplantation (2014), Persian Organ procurement unit model, national and international courses, social awareness activities, media engagement, support by celebrities and volunteers, collaboration with ministry of education and MoUs with cinema affairs and municipal played a very important role to shift the position of Iran from 42<sup>nd</sup> rank in 2004 to 31<sup>st</sup> rank in 2015 in terms of rate of organ donation across the world.

Understanding the western approach of organ donation, learning from them and tapering the learning curated to the cultural practice of Iran helped to step up the organ donation program in Iran. Training by TPM at the beginning, learning many things from Gift of Life, adjusting their achievements with their religion, culture and then designing a network and a system based on the same was the crux of success of all the models.

The chairperson added that different factors need to be taken into consideration suiting each country's cultural needs to promote organ donation in a particular country.

#### **China Model- How has China moved forward with deceased donation programme** *Speaker:* **Ms. Wenshi Jiang**

Chairpersons: Dr. Nitin Kekre, Dr. Narayan Prasad & Dr. Ashish Sharma

In her session Ms. Wenshi Jiang touched upon the role of Organ Procurement Organization {OPO} in the organ donation and transplant scheme in China. Through China Organ Donation Administrative Centre, OPOs came into place in 2013 and as of 2015, 113 OPOs have been developed in China

Ms. Wenshi further went on to explain the setting up and developing OPOs. OPOs are divided among different regions. A medical professional from transplant unit is in-charge of detailed operation of OPO. Medical experts from the ICU departments can be the directors of the OPOs. To facilitate the process of organ donation, procurement and transplantation there are two coordinators – one from the Red Cross society and another from OPO itself. A person is certified as a coordinator after thorough training and clearing an examination. The Red Cross coordinator could be a nurse or a doctor while the OPO coordinator can be a healthcare professional.

When a family agrees for organ donation, the hospital staff has a one minute silence memorial service for the body before retrieval of the organs. For the allocation of the organ a computerized system organ registry and procurement process is used to find a suitable donor. A message is automatically sent to the top 5 patients in the waiting list. To transport the organ if needed a green channel for organ transportation is created. For the same the department of health and family commission, civil aviation, police department, transportation department and railway department are involved in the process. Ms. Wenshi touched upon cases where the family has approached the hospital to donate the organs of their loved ones even when they are not brain dead.

She emphasized the need to respect the donor and its family for a successful organ donation program. As it is the donor and his family that are the reason for some lives being saved. Each region has its own memorial garden and Red Cross society has memorial activities for the donor.

#### Directed Deceased Donations Speaker: Dr. Sudeep Naidu Chairpersons: Dr. Nitin Kekre, Dr. Narayan Prasad & Dr. Ashish Sharma

Dr. Sudeep Naidu presented case stories where the family of deceased asked for directed donation when they were presented with the option of organ donation. All the four cases presented by him showed that directed donation is illegal, but it has always existed. He explained directed donation under two categories: one is directed, where the request is made by a donor family to transplant to a specific recipient. While in conditional the donation focuses to a particular class of people.

The donor families of a brain death patient have never supported directed donation. If we allow solicitation in any case of donation then a normal deserving patient, who doesn't have the capability to solicit, will never be able to get an organ. Directed donation challenges the altruism and impartial equitable distribution element in the life saving cause of organ donation.

Dr. Naidu also tried to present another view i.e. if we say we are allowing a living donor to a specific person then why do they go the state registry after death. The reason for the same being that organs are the country's resource. Today if we allow directed donation it might catapult it to bizarre requests in the future.

Dr. Naidu ended his session by sharing the case of a website called 'life shares' – where all the people registered are whites, rich, have access to internet and would donate to someone who is in their network. He concluded that directed donation should be taken into consideration from case to case and one cannot be dogmatic about it.

The chairperson Dr. Nitin Kekre gave his inputs on organ donation in Nepal. He emphasized that the organ donation system in Nepal was very similar to the programme in India even though it started only on 2008 with help from Australia. When India stopped its programme of paid transplant the same happened in Nepal. There is no paid and unrelated donation in Nepal too. Dr. Kekre shared a scenario when government made the dialysis free and that time many patients started to opt out from the transplant and preferred to stay on dialysis as long as possible.

#### ORGAN DONATION AND TRANSPLANTATION IN SAARC REGION

A. Kidney Transplants in Kidney Foundation Bangladesh

Speaker: Dr. Harun-Ur-Rashid

Chairpersons: Prof. K. L. Gupta, Dr. P. Soundararajan

Dr. Harun recounted how he started the Kidney Foundation Hospital in Dhaka. He said that 18-20 million citizens of Bangladesh suffer from CKD. Bangladesh has a law on organ donation that allows deceased donation and prohibits unrelated donation except from spouse and donation from people with hepatitis and HIV are not allowed. In 1982 they did the first transplant and till 2016 more than 1500 transplants have been successfully done in the 10 transplant centres.

He said in 2002 June he started out in a rented place with 7 staff and slowly built his own hospital. He listed the main causes of CKD, gave examples of the living donations and explained a study on the immunosuppressants and infections post surgery. He said that the main obstacles to deceased donations are the lack of awareness, poor ICU setup and absence of trained transplant coordinators. He suggested that some effort has to be made to create a positive interest to transplant among the doctors in Bangladesh.

# **B.** Our Story / Success and Hurdles for Organ Donation in Nepal Speaker: Dr. Rishi Kumar Kafle Chairpersons: Prof. K. L. Gupta & Dr. P. Soundararajan

Dr. Kafle said that their transplant program started in 2008, transplants between biologically related donations only. This was due to a lot of organ trafficking fear. Later the Government began a program of free dialysis and patients preferred to continue with dialysis done vis-à-vis getting a transplant. The Government subsidised transplants for blood relation live donations @ 500,000 Nepali Rupees.

He elaborated on the New Plan -

- 2 lakh Nepali Rs to be given to institution
- 1 lakh Nepali Rs to be given for immunosuppressants
- Free transplant in govt hospital only

In Nepal three private hospitals are doing transplants. The Government is now under pressure to make immunosuppressants free. Public have misconceptions that the donated kidney will grow back hence more awareness is needed

#### **C.** Sri Lanka Story of Deceased Donation & Kidney Transplantation programme Speaker: Dr. Niroshan Seneviratne Chairpersons: Dr. Rezvi Sheriff, Dr. Manish Rathi & Dr. Manoj Jain

Dr Seneviratne gave an account of the situation in Sri Lanka. He said that annually 63000 patients suffer from CKD, of which 20000 CKD is of unknown origin and have been identified in dryzone farming regions with heavy use of agrochemicals. Nearly 5000 CKD patients die annually for lack of treatment.

He said that the 1<sup>st</sup> deceased donor transplant was conducted in 1999. Most patients go overseas for treatment, especially for transplants. In the 21<sup>st</sup> century Sri Lanka took some positive steps to promote organ donation, such as Kandy General Hospital, Sri Jayawardenapura Hospital came up as Transplant Units, Peradeniya Hospital set up its Paediatric transplant unit. In 2012, the technique of Laparoscopic nephrectomy was established in the country. In 2015, they launched several measures for public awareness such as launch of Donor Cards and Driving License Pledge, after this the deceased donor program picked up.

Dr. Seneviratne said that in 2016, there were 8 Transplant Centers, 3000 live donor transplants have been performed & 175 deceased donor transplants have been carried out. However the country is lacking a National deceased Donor Program / Organ Procurement Program. Currently Sri Lanka's rate is 1 / 1.5 PMP.

#### D. Organ Transplantation in India

#### Speaker: Dr. Sunil Shroff

Chairpersons: Dr. Rezvi Sheriff, Dr. Manish Rathi & Dr. Manoj Jain

Dr. Shroff gave a comprehensive account of the Status of Organ Donation in India. He said that after the Transplantation of Human Organs Act was passed in 1994, India slowly reached a leading place in organ donation in the region. Deceased donor transplant remains 10% of transplant in kidney and we need to increase the contribution. There still continues to be a wide gap between the demand and the source of organs. India has the 2<sup>nd</sup> largest living liver Transplant program. We perform 8000 Transplants Vis-à-vis 6000 in US. In the case of liver, 25% of liver transplants are through deceased donations. Around 200 heart transplants are done in India.

He described how in the last 5 years, Organs donated through deceased organ donations have increased by 4 times. Many NTORCs are contributing to the program, classic example is Kerala. Many states have started organ donation programs. A national and regional system of organ donation is in place with NOTTO and ROTTO and SOTTO. A few NGOs have helped in creating a positive image of organ donation. Paradigm shift seen in TN & AP wherein the families now ask for organ donation. The media and the police have also helped through reporting and creation of Green corridors.

He said that there are still areas of concern namely the perception of Brain death among medical professionals, not many centres trying for DCD for India, frequent scandals reported cause setback to the program and conversion from donor family of Islam faith still remains very low.

In 2017, overall, in India, conversion rate is ~ 65%, with 400 Transplant centres in India and a need of 1500 Transplant centres. This can be achieved if "Donations should become Usual, not Unusual".

#### Panel Discussion- Religion and Organ Donation, Sri Lanka, Iran, Nepal & Bangladesh Speakers: Dr. Rezvi Sheriff, Dr. Omid Ghobadi & Dr. Bishwa Raj Joshi Moderators: Dr. Avnish Seth & Mrs. Lalitha Raghuram

Mrs. Lalitha Raghuram highlighted that even though India has progressed in organ donation over the past few years, religious beliefs continue to serve as a barrier, thereby preventing the larger population from endorsing organ donation.

Dr. Rezvi Sheriff (Sri Lanka) and Dr. Bhandari (India) spoke on the plans of the National Agencies. Dr Sheriff said that Quran mentions that saving one life is like saving the entire human race. It should be an act of charity. Organs should not be bought or sold.

Dr. Omid Ghobadi (Iran) reinforced the same views. People in Iran had a fear if their organs are separated in this life, then in the after-life, they get salvation only if the organs report to God. Due to this belief, people were hesitant to donate as they believed the organs would get separated if donated and transplanted into others. Dr. Omid Ghobadi explained that they could overcome this problem by

referring to the "Mahad", their Holy Book, from which it was interpreted that even if organs are separated, they come together to report to God.

Dr. Bishwa Raj Joshi (Nepal) said that the ultimate solution was to engage religious leaders in the long run, in order to ensure smoother running of the program.

Mrs. Lalitha emphasized that family gurujis and other religious leaders must be taken into the loop for counselling as they do not know much about organ donation but they are quite influential on people's thought process.

Dr. Shroff added that in India, people privately agree to organ donations however fail to do anything publicly for fear of a public backlash from the community. He asked the Iranian delegates if any international Islamic group of leaders could be approached for their endorsement of organ donation especially since organ donation consent remains quite low among the Islamic community in India. To this, Dr. Katayoun replied that Islam itself being divided into Shias and Sunnis, there is a fatwa issued by the Shiite leaders and all will follow it; however it is very difficult among Sunnis as they have a large number of religious leaders with varied opinions.

Narrating an incident which served as a challenge and a lesson, Lieutenant Colonel Sandhya, Transplant Coordinator, Army Hospital R&R, Delhi, said, "A soldier from Haryana, consented to the donation of his deceased father's organs at our hospital. However, his older sister refused, stating that she would agree only if we could ensure that the organs were transplanted into a Brahmin's body - which was not in our hands."

The issue of rebirth, which is predominant in North India, is another factor preventing people from donating. "I have had cases of families refusing a donation fearing that their kin would be born without that organ in his next life," said a nephrologist from Vellore. Barely 65 percent of India's population is convertible by an experienced nephrologist or counsellor, she added.

Dr. Avnish Seth mentioned that as part of the NDTV 'More to Give' campaign, they had brought together various religious leaders who spoke to dispel myths on organ donation.

## 17 March 2017, Day 2 – Afternoon Session

#### **Training and Capacity Building**

#### **A.** Capacity Building through surgical training Speaker: Dr. Sonal Asthana Chairpersons: Dr. B. Arun Kumar & Dr. Nirmal Bhandari

This talk was done via skype by Dr. Sonal from Bengaluru. He spoke of the need of large transplant centres, a skilled set of retrieval surgeons and transplant surgeons, with additional skills of Handling stress, High Tolerance and team work. Burnout is the biggest problem faced by Transplant Surgeons and by the hospitals,

He mentioned that today there is no established mechanism for training. Since most of the transplants are done in private sector, it is not conducive for training. Surgical training is more likely to be seen as a technical exercise and no research is being done in transplant field.

He said the solutions in training of surgeons can develop a large pool of skilled surgeons. He suggested-

- There should be targeted training
- There should be a structured program
- Structured course in Organ Recovery is needed

He highlighted the recently conducted Oxford Organ retrieval course with NHS and MF

- Along with the course they had setup Organ retrieval webinar
- 2 of the trainees have successfully setup heart transplant programs
- Before the course 5% were involved in transplant activity. After the course, greater than 80% are now involved.

He suggested that the Indian National Agency NOTTO and leading NGO – MOHAN Foundation should jointly conduct "National Organ Retrieval workshop", develop a standard curriculum, always include a webinar. They should also come up with a long term structured plan for surgical trainings.

#### B. Capacity building to improve donations in China

#### Speaker: Dr. Wenshi Jiang

Chairpersons: Dr. Sandeep Agarwal & Dr. Ananth Kumar

Dr. Wenshi began by saying that following are the requirements for capacity building –Organisational Structure & Legal Framework.

She said that in China the Donor Registry is in place under the Ministry – 190,000 people have signed up. Simultaneous National Campaigns for Organ donation have been conducted, but with the population being 1.4 billion it is a challenge to reach everyone.

Within the medical fraternity, there are difficulties and lack of awareness among the ICU experts. Therefore OPO branch offices are now in donor hospitals. This has helped in conducting training and leadership programs. Now some programs are Post Graduation courses in Universities. These graduates also help in starting separate OPOs in China.

Ms. Wenshi said that the key to success is through Support from Govt & Individual Leaders in this field.

#### **Training Our Manpower - Transplant Coordinators' Training Programme** Speaker: **Dr. Sumana Navin** Chairpersons: **Dr. Sandeep Agarwal & Dr. Anant Kumar**

Dr. Sumana Navin divided her talk into three aspects which was the need for trained Transplant Coordinators, the importance of a structured high quality and cost-effective training programme and the impact of MOHAN Foundation's training programmes. She reported that from December 2009 to February 2017, MOHAN Foundation has conducted a total of 43 trainings and has trained 1416 transplant coordinators.

#### The Need

- She pointed out from the THO (Amendment) Act, 2011, lays down the requirement for a transplant coordinator. In India there are close to 400 transplant centres, which shows that there is a requirement for approximately 1000 transplant coordinators in India.
- She listed out the various skills which all transplant coordinators must possess.

#### The Structure

- She pointed out that this training programme is the first of its kind in South Asia
- She explained about the three types of trainings conducted by MOHAN Foundation which is the one week, one month and one year trainings and supported by Tata Trusts and SBI Foundation.
- The trainings are focused on Core Components such as Medical, Legal, Ethical and Religious, Grief Counselling, Transplant Coordination, Field visits and Projects.
- Of all the transplant coordinators trained so far 37% were Nurses.
- She highlighted National and International Collaborations with MOHAN Foundation in capacity building. National Collaborations National Organ & Tissue Transplant Organisation, a total of 9 training programmes have been conducted under the aegis of NOTTO.
  Collaborations with State organ donation and transplantation bodies, Hospitals and other entities International Collaborations NHS Blood and Transplant, UK, Gift of Life Institute, Philadelphia, USA and The International Society of Nephrology American Nephrologists of Indian Origin (ISN-ANIO).
- She introduced a programme which is coming soon for Qualified Senior Transplant Coordinators with a minimum of 3 years experience. They are eligible for a two week fellowship programme at Gift of Life Donor Program & Albert Einstein Medical Centre Philadelphia, USA.
- She explained about the one year e-learning course which is ideal for working professionals. It consists of 60 modules and 35 video lectures by National and International faculty. It also consists of

Interaction with faculty through contact sessions for soft skills and counselling, application oriented visits and projects.

#### The Impact

- Rajiv Gandhi Government General Hospital, Chennai Transplant coordinators counseled 214/221 families of brain dead patients resulting in a conversion rate 64% from February 2010 – December 2016.
- Osmania General Hospital and Gandhi Medical College and Hospital, Telangana Transplant coordinators from December 2014 to December 2016 have counselled 145 families of brain dead patients, out of which 114 families said 'Yes' to organ donation.
- She pointed out that trained transplant coordinators across India have successfully done 745 deceased donations, with 3937 organs and 492 corneal and skin donations (Dec 2009 Dec 2015).

She concluded by saying that trained transplant coordinators make a significant impact on the success of transplant programmes and that a structured training programme tailored to India's needs is necessary to create an effective transplant coordinator.

#### NEW IN TRANSPLANTATION

## A. DCD to increase donation rate – perspective from Australia – DCD organ retrieval and preservation

#### Speaker: Dr. Ruth Hardstaff Chairpersons: Dr. R. Jayaraman, Dr. C. Ilamparuthi & Dr. Ashish Sharma

The main aim of the session was to understand how to expand the donor pool by including the DCD donations. In the session Dr. Ruth explained that generally DCD donors do not fulfil brain stem death criteria and most of the ICU patients are on circulatory respiratory support. A doctor needs to make an independent clinical decision if the ongoing support is either futile or not in the patient's best interest.

Usually it is difficult to get consensus on the definition of circulatory death. Certification of death is done by the treating ICU staff and not the organ retrieval staff to avoid any conflict of interest. Cessation of circulation, apnoea and arterial line needs to be taken into consideration. The usual causes of contraindications are malignancy, infections, end organ failure, diabetes, hypertension, smoking, cardiovascular disease and other co-morbidities. At the time of withdrawal of cardio respiratory support and at agreed regular intervals the pulse blood pressure and oxygen saturation must be noted. A 5 minute intervals is suggested to note the readings if the patients is stable otherwise a 1 minute interval in case the patient is unstable.

After cessation of circulation there is a "stand off period". A period of 2-5 minutes is waited to make sure that circulatory death has definitely occurred. After which, the ICU doctor can certify the patient death. The patient is then transferred to the operating theatre.

The initial fluid should be a less viscous organ preservation fluid such as Marshalls or HTK solution. This acts as a flush to wash out the blood from the organs and to prevent clots from forming which impacts on reperfusion after transplantation. 4-5 litres of fluid should be used depending on the size of the patient. If cold storage is going to be used, University of Wisconsin fluid was a suggested fluid. Around 4-6 litres should be perfused, depending on the size of patient and colour of fluid draining from IVC vent. HTK is generally used for the machine perfusion.

Dr. Ruth concluded by saying that there was significantly increased available organs for transplantation in Europe, US and Australia through DCD. Warm ischaemic time was critical. Machine perfusion is very essential for lungs and hearts while it also seemed beneficial for livers.

#### B. Is robotic assisted kidney transplant the future for Asia

Speaker: Dr. Anant Kumar

#### Chairpersons: Dr. R. Jayaraman, Dr. C. Ilamparuthi & Dr. Ashish Sharma

Dr. Anant Kumar explained the advantages of Robotic Kidney Transplant being fewer requirements of analgesics, no lymphocele and it had 3 % wound infection versus 28% in open transplant. While it also had some disadvantages, which were, longer anastomosis time, para transplant hernia, intraperitoneal placement and difficult biopsy. He showed a video

Some of the challenges faced in robotic kidney transplant were that the kidney would slide due to smooth surface of peritoneum. It also required longer secondary warm ischemia and intra operative cooling. Another challenge was the redocking of robot after kidney is placed into the peritoneal cavity.

Dr. Anant Kumar also explained few measures to overcome the challenges. The docking can be done between the legs while redocking was not necessary. 300 cc of ice slush could be used in the peritoneal cavity to maintain the surface temperature at 22 degree Celsius. The results from robotic surgery were good when WIT was less and if the surgery was done by experienced and fast surgeons.

By 2016 there were 20 centres that are practicing robotic transplant globally and 5 of them are in India. Majority of the robotic transplants in India are done by Dr. Modi and Dr. Ahlawat. Dr. Anant Kumar said this type of surgery has gained some support, in 2016 more than 200 robotic transplant surgeries have been done.

#### C. DCD Heart Donation and Transplantation Speaker: Dr. K. R. Balakrishnan Chairpersons: Dr. R. Jayaraman, Dr. C. Ilamparuthi & Dr. Ashish Sharma

Dr Balakrishnan began by recalling the first heart transplant that was a DCD done by Christiaan Barnard. He said that the first heart transplant in India was done in KEM Hospital, Mumbai in 1968. In the western world with the success of DBD, doctors started looking at patients with cardiac death as organ donors. He then explained the Maastricht criteria.

He said that more than 80% of heart transplants happen in Chennai and this was only due to the smooth functioning among all stakeholders and standardised protocols. As Tamil Nadu increases its donation rates, he is able to save more patients. In 2016 his centre did 74 heart transplants. In India there are certain constraints – like the lack of use of VAD and pumps because they are expensive, absence of a good system of organ transport. Many organs have been wasted due to this. He said he has lost 45 patients on the waitlist but at the same time he has done 158 transplants.

Further he explained the growth of the organ care systems or perfusion systems and how his team has developed a simple and affordable organ care system. He explained how the donor heart functioning can be measured by checking the levels of lactate.

At the end he suggested that it is time to initiate and implement a centralised organ assessment and procurement team.

#### The Year That Was – Reminiscences & Inauguration

Mrs. Lalitha Raghuram started the program with a prayer and the dignitaries were invited to light the lamp and inaugurate the ceremony.

Welcome address was given by Dr. Georgi Abraham.

Dr. Shroff shared the highlights of the year 2016. He spoke about how the deceased organ donation program has progressed in the country – from 196 donors in the year 2008 to 570 in 2015 and to 800 in 2016. He thanked the media, the doctors, the hospitals and the various NGOs working in this field.

Dr. Avnish Seth shared an update on the "More to Give" campaign which was initiated in 2016 and lasted till Feb 2017. He spoke about how this campaign has successfully reached out to lakhs of Indians. The event had included lots of on-ground activities including walkathons, endorsement by Irrfan Khan, endorsement by various inspiring persons from various fields, various panel discussions especially during the Times of India campaign in August 2016 and during the National Organ donation day in November 2016. The event culminated on 14<sup>th</sup> Feb 2017 with on-ground awareness activities during the Kalaghoda festival in Mumbai and the "Dil Deke Dekho" Valentine day campaign. The campaign also included a panel discussion by various religious leaders from different communities endorsing organ donation.

Mr. Badal Rag spoke about the awareness activities and events conducted during the fortnight long Times of India Campaign from 1<sup>st</sup> August to 13<sup>th</sup> August 2016 in association with Kokilaben Dhirubhai Ambani Hospital. He spoke about how they had an overwhelming response thanks to the sustained campaign. The print media carried lots of facts, articles and inspiring stories, thereby spreading awareness on the subject during the campaign. They hosted public seminars, flash mobs and school activities. The success of the campaign could be measured by the fact that all Indians now believe that 13<sup>th</sup> August is World Organ donation day.

Mrs. Lalitha Raghuram shared updates on activities of MOHAN Foundation during 2016. She spoke about the various awareness activities and the training programs conducted by MOHAN Foundation. She also went on to share highlights of awards and Puraskars received by Mrs. Bhavna Jagwani, Dr. Sumana Navin and herself, in recognition of the yeoman contribution made by them.

Prof. Vimal Bhandari then went on to share updates on NOTTO's activities, workshops and various other highlights. He said that NOTTO has taken the assistance of local NGOs and experts to bring standardised training programs in upgrading skills. They also conduct national level awareness programs and competitions to generate interest amongst the public.

Dr. Anant Kumar also shared updates on ISOT's activities and events.

Dr. Shroff gave the Vote of thanks in which he thanked all those present and all those involved in the field of promoting organ donation.

The evening ended with a beautiful medley of folk dances of Tamil Nadu called "Namma Ooru Manvaasam" presented by the staff of MOHAN Foundation, followed by dinner.

## 17<sup>th</sup> March 2017






























### 17<sup>th</sup> March 2017





























#### Day 3 – 18 March 2017, Morning Session

#### Chief Guest – Dr. J. Radhakrishnan, IAS, Principal Secretary, Health and family Welfare Deaprtment, Govt. Of Tamil Nadu

Dr. J. Radhakrishnan was unable to come for the Inauguration, so he spent some time with the faculty and delegates the next day morning. He spoke on how organ donation and transplantation is a team work right from the Government, hospitals both public and private and NGO and counsellors. The growth of the program has been possible because of the continuity of support from Government with the establishment of a Society for Organ donation called TRANSTAN and non-interference in the day to day activity of organ donation. He felt that the challenges were the need for training and upgradation of government hospitals and the trained ICU and transplant doctors.

The success in Tamil Nadu can also be attributed to the vibrant Public-Private partnerships, a transparent system of organ allocation and regular meetings with stakeholders to discuss any issues. At present Tamil Nadu wants to fast-track paediatric liver program. Tamil Nadu is the only state having a dedicated officer in the Police to facilitate organ donation in medico-legal cases. It also has a supportive media which has helped to develop a positive mind-set about organ donation in the public.

#### **Round Table discussion -**

**Guidelines for various medical issues in Transplants** 

#### A. Kidney Paired Donation Transplantation To Increase Living Donor Kidney Transplantation In India: Recommendations of Indian Society of Organ Transplantation meeting

## **Authors : Vivek B Kute** , Anant Kumar, Manisha Sahay , Viswanath Billa and Dharmednra S. Bhaudaria

**Abstract:** Kidney paired donation transplant is legal, cost effective, rapidly expanding modality with best long term outcome to increase living donor kidney transplantation (LDKT) by 25 % in India. The quality and quantity of KPD matching will be better in national program compared to single center program due to large donor pool. Each incompatible pair should be given awareness and counselling about KPD. Significant benefits can be achieved by <u>providing better-matched donors for HLA mismatched compatible pairs through KPD.</u> Cold ischemia time up to 16 hours has little impact on living donor kidney transplant outcomes in the era of KPD. Living kidney donor age between 18 to 65 years has little impact on long term outcome of living donor kidney transplant. There was no statistically significant difference in the short term outcome of KPD with poor HLA matching compared to living related donor kidney kidney

transplantation. Waiting time in KPD is significantly less for easy to match pairs compared to deceased donor kidney transplantation. National Organ and Tissue Transplant Organization should start the national KPD registry.

**Keywords:** Kidney paired donation, living donor kidney transplantation, deceased donor kidney transplantation

Words in manuscript: 2330 Words in abstract: 200

#### **Manuscript**

#### Introduction

The Indian chronic kidney disease registry in 2010 reported that a majority of end stage renal disease (ESRD) patients (61%) were not on any form of renal replacement therapy (RRT) at the time of reporting, 32% on hemodialysis, 5% on peritoneal dialysis and only 2% were being worked up for kidney transplantation [1]. There is huge disparity between supply and demand of the transplant organs anywhere in the world, including India. All efforts should be made to increase the supply of required organs to the waiting transplant patients. Single centre KPD is practiced in India in absence of national Kidney paired donation (KPD) program [2-29]. Table 1 shows key elements of success of single center KPD program at Institute of Kidney Diseases and Research Centre, Dr HL Trivedi Institute of Transplantation Sciences, Ahmedabad, India [2-10]. Kidney paired donation is one of the easily available option which may increase living donor kidney transplantation (LDKT) rate by 25% in India [5]. Kidney paired donation will be facilitated if we have a national KPD programme, where all participating centers provide details of those patients who do not have compatible living donors due to any reasons and are therefore waiting for deceased donation. ABO compatible kidney transplant is the best renal replacement therapy (RRT) modality for ESRD patients in resource limited developing country like India where morbidity and mortality on long term dialysis is very high. Access to RRT is mainly prevented by poverty. Upto 90 % of kidney donors are living donors and deceased donor kidney transplantation (DDKT) is in initial stages and difficult to expand despite immediately. Outcome of LDKT is always better than DDKT. Living donor kidney transplantation via KPD can be performed at any transplant centre without need of extra facilities like in ABO incompatible kidney transplantation (ABOiKT), desensitization protocol and DDKT. Worldwide, KPD is rapidly increased source of quality organ in the last decade [30-36].

Advantages of single center KPD program: Donor transport or transport of kidney not required, surgical care is uniform, cold ischemia time is less, administrative cost is less, follow up of donor-recipient pairs is in familiar hospital

Advantages of multi-center KPD program: quality and quantity of matching is better due to large donor pool and computer allocation, surgical team requirement is less to carry simultaneous surgery in long chain, transplant rate is better for difficult to match donor-recipient pairs

#### Awareness and counselling about KPD

The recent study reported that 90 % of incompatible donor-recipient pairs are not aware about KPD as cost effective kidney transplantation options with best long term outcome [4]. Each incompatible pair should be given awareness and counselling about KPD in a standardised format. This counselling can be performed during dialysis. They should be explained advantages and disadvantages of KPD vs ABO iKT, desensitization therapy, DDKT and maintenance dialysis in terms of cost and long term outcome. This counselling can be performed by dedicated KPD team, transplant team, transplant co-ordinator, dialysis technician, and social worker, medical and paramedical staff, transplanted patients and combined efforts of all of them depending on the local resources. The social networking site can also help in increasing awareness and counselling. Every attempt should be made to prevent unequal outcome after kidney transplant due to donor related factors, patient related factors, transplant surgery and transplant centres. Each high risk patient with comorbid condition like diabetes heart disease, infections should be counselled that unequal outcome after kidney transplant can happen due to patient related factors. The screening for occult infections and heart diseases should be performed before kidney transplant in all diabetic and high risk patients with non-invasive methods and conventional coronary angiography.

#### Single centre, multicentre, state and national KPD registry [37, 38]

KPD database of incompatible pairs should include information on <u>demographics</u>, <u>physical</u> <u>characteristics</u>, human leucocyte antigen (<u>HLA</u>) <u>profile</u>, <u>unacceptable</u> and <u>amenable</u> antigens <u>, discretionary exclusion criteria</u>, <u>certification of registration</u>, <u>suspension or withdrawal</u> date and reason, <u>dates of registration and update</u>, <u>contacts at recipient's centre</u>.

The demographics of patient should include data about date of birth, gender , weight in kilogram, height in centimetre , body mass index (BMI) , cause of ESRD,CMV serology, donor relationship with patient, panel reactive antibody , atypical risk factors, if any ( like diabetes, infection , heart disease, and other co-morbid conditions). Reason for incompatibility with co-registered recipient should be included (ABO incompatible, lymphocyte cross match positive, flow cross match positive, luminex donor specific antibody positive, donor is compatible and joined KPD for better HLA/ donor age matching, altruistic). Financial barrier is more common cause to prevent access to kidney transplantation in India.

The demographics of donor should include data about date of birth, gender , weight in kilogram, height in centimetre , body mass index, blood pressure , number of drugs used to control blood pressure, urine protein, creatinine clearance by diethylenetriaminepentaacetic acid (*DTPA*) renal scan , number of renal artery and vein on computerised tomography (CT) renal angiography, cytomegalo virus (CMV) serology, hepatitis C virus, hepatitis B virus, human immunodeficiency virus serology by an enzyme-linked immunosorbent assay, donor relationship with patient, atypical risk factors, if any ( previous infections like tuberculosis , heart disease, and other co-morbid condition). One donor-recipient pair should be allowed to register with more than one KPD program and more than one donor when required.

#### Recipient's discretionary exclusion criteria should include following information.

Donor travel distance limitation in kilometre should be included. If a transplant can be arranged with a donor who is unwilling or unable to travel to the recipient's location, would this recipient accept having the donor's kidney shipped to the recipient's transplant center? What are the highest numbers of HLA mismatches that this recipient will accept? What is the lowest donor age that this recipient will accept? What is the highest donor age that this recipient will accept? What is the highest donor relies on medications to maintain an acceptable blood pressure, what is the highest number of medications that this recipient will accept? What is the lowest creatinine clearance rate that this recipient will accept? What is the highest donor BMI that this recipient will accept? If this recipient has type O blood, could the recipient accept a type A2 donor? **Certification of the patient's and donor's registration** 

The transplant coordinator, registrar, authorised person or program director in the registering transplant center must attest to the following statement: 1] The recipient requires kidney transplant. 2] The recipient's and the donor's blood group and HLA profile are correct, and the data-entry has been double-checked by a second person.3] The donor meets all published prerequisites for being listed in this registry, including those that are not specifically documented on this registration form. 4] The donor has an emotional, noncoercive, non-remunerative relationship and first degree relative of the co-registered recipient.5] Medical fitness for transplant surgery and kidney donation in the standardised format is completed by transplant team consisting of transplant physician, surgeon, anaesthetic, HLA lab person, psychiatrist, transplant co-ordinator, social worker and other medical speciality like cardiology, gynaecologist when required and medical charts are provided for review.6] This study is /will be approved by government and institutional ethical review board and donor-recipient pairs consented to KPD transplantation. The transplants are as per Transplant human organ act, India, the declaration of Helsinki and declaration of Istanbul principles.

#### What is impact of HLA matching on long term outcome of LDKT?

Significant benefits (better long term survival and lower infections due to less potent immunosuppression in Indian environment) can be achieved by <u>providing better-matched</u> <u>donors for HLA mismatched compatible pairs through KPD [24]</u>.

#### What is impact of cold ischemia time $\leq$ 16 hours on long term outcome of LDKT? [39]

Cold ischemia time up to 16 hours has little impact on living donor kidney transplant outcomes in the era of kidney paired donation. Donor travel rather than kidney transport is best suitable for the Indian environment in case of multi-centre program. However, the participating transplant teams should make the decision by consensus about kidney donor vs kidney transport as per local resources and logistics.

#### What is impact of living donor age on long term outcome of LDKT? [9, 40, 41]

Kidney transplant recipient of older deceased-donor kidney have decreased long term kidney graft survival. However, the impact of donor-recipient age difference on living donor kidney transplant outcomes, where donors are older than recipients, remains unclear.

Kute el al. [9] reported a study examining the association of the difference in donor and recipient age on outcomes following living kidney donation. The authors presented results based on a large single center experience and examined the primary outcomes of graft and patient survival and acute rejection rates based on age difference. The authors reported no significant difference in recipient outcomes based on this age mismatch and concluded that this supports use of KPD in age discrepant pairs. The limitation of this study was small sample size. The finding that larger donor-recipient age differences are not associated with worse outcome is reassuring. Given the relative numbers of related vs KPD transplants, it is far more relevant that older donors (usually within families) are just as good as younger ones. The better immunological match may counteract the effect of higher donor-recipient age difference in case of parents as kidney donor.

The age difference between the exchange donors should not be the key issue for KPD. The real issue in the likelihood of transplantation for most KPD participants is whether transplantation from a living donor (irrespective of the age) is going to be the best choice compared to continued waiting on dialysis since the mortality is higher on long-term dialysis.

The analysis using data from the Australia and New Zealand Dialysis and Transplant Registry, the US Renal transplant data System and Indian experience showed that living kidney donor age

between 18 to 65 years has little impact on long term outcome of living donor kidney transplant outcomes. This finding is useful in single centre KPD program when donor pool is small. Living kidney donors, who are up to 30 years older than their recipients, provide kidneys of excellent quality. These findings are of relevance when considering KPD programme because the chance of finding a suitable match should not be unnecessarily limited by unjustified restrictions on the perceived disadvantage of high donor-recipient age difference.

## What is impact of HLA matching in KPD vs living related donor kidney transplantation (LRDKT)?

There was no statistically significant difference in the short term patient and graft survival outcome of KPD with poor HLA matching compared to LRDKT with better HLA matching. This can be due to steroid and rabbit thymoglobulin based induction therapy and maintenance triple immunosuppression with steroid, tacrolimus and mycophenolate.

#### What is waiting time in KPD vs DDKT?

Waiting time is significantly less (1-3 months) for easy to match pairs compared to DDKT [3-5, 42]

Waiting time can be reduced for hard to match pairs compared to DDKT with the innovative ways in KPD. Transplant rate for difficult to match pairs like O blood group and sensitised patients can be increase by compatible pairs ,longer chain , KPD + desensitization, KPD + ABOiKT, use of A2 donor to O patient , expanding the number of acceptable mismatches, national , international ,global kidney exchange and living-deceased donor list exchange [43]. Compatible pairs can increase quality and quantity of KPD matching even in the single center program and improve long term patient and graft survival and outcome

#### Easy to match pairs should be encouraged for KPD

In a high volume LDKT program or national KPD program , all A and B group donor recipient pairs without high level donor specific antibody (DSA) can be transplanted with KPD within reasonable waiting time with manual allocation, without depending on using computer allocation . Such easy to match pairs (A and B) should be excluded from ABOiKT or DDKT/list exchange due to patient death and with functioning kidney graft, due to infections being common even in ABO compatible LDKT in developing countries.

#### Need of legal amendment in THOA, India [2-10]

The transplantation of human organ act and law should be amended for clear cut permission for compatible pairs, living –deceased donor list exchange, extended family member, and International KPD.

#### Who should start KPD registry

- All data of incompatible donor-recipient pairs should be entered in National Organ and Tissue Transplant Organization registry (NOTTO R) as mandated under THOA and its rules, India. National Organ and Tissue Transplant Organization (NOTTO) should help in educating stakeholders for entry of data as and when required.
- 2. Website and software for KPD transplant should be managed and run by NOTTO through NOTTOR. If required, a dedicated staff can handle KPD program.
- 3. All KPD activities to be directed and supervised by NOTTO. Participating transplant centers should interact directly with NOTTO.
- 4. KPD transplant should be allowed among distant relation (like cousins, uncles and aunts) in addition to "first degree relatives" as already allowed for direct transplant.
- 5. For KPD transplants, clearance may be done by single authorization committee for all available pairs, instead of collecting clearance from individual states of donors/recipients
- 6. Directive from government to authorization committee for allowing KPD within distant relatives and domino/ altruistic donors may be given for compliance
- 7. NOTTO may assess feasibility and functionality for incorporation of "KPD software" of Dr Michael Rees in the existing registry of NOTTOR.
- 8. Guidelines and rules related to all KPD transplant may also be framed by appropriate authority.
- Organize KPD sequentially :Hospital < city < district <state < State Organ and Tissue Transplant Organization (SOTTO) < regional Organ and Tissue Transplant Organization (ROTTO) < NOTTO</li>

#### Conclusion

Kidney paired donation transplant is legal, cost effective, rapidly expanding modality with best long term outcome to increase LDKT by 25 % in India. The quality and quantity of KPD matching will be better in national program compared to single center program due to large donor pool.

**Disclosure:** These are recommendation on KPD transplantation after *Indian Society Of Organ Transplantation* (ISOT) midterm meeting at Chennai on 18 March 2017 and "National Workshop on Kidney Paired Donation" on 29-04-2017 at Pullman Hotel, Aerocity ,New Delhi by ISOT

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Table 1: Key elements of success of our single center KPD program [2-10]			
Awareness and counseling of KPD by dedicated KPD team and transplanted patients			
Maintain KPD registry of incompatible pairs			
No administrative charges for KPD registration and match making			
Uniform pre-transplant evaluation and post-transplant care			
Standardization of HLA laboratory and expert transplant coordinator			
Complete work up of pairs before allocation avoids chain collapse			
Immunological compatibility documented by negative lymphocyte and flow cross match $\pm$ DSA			
Non-anonymous allocation			
Exchange kidney of similar quality (anatomy, function, and immunology)			
Dedicated transplant team to address logistic problems but no dedicated staff for KPD			
Simultaneous transplant surgeries avoid risk of donor reneging			
Attempted to improve our program using key features of other successful KPD program			
All are ABO compatible transplants			
Bonus for sensitized, difficult to match ,pediatric patients , donor of similar age group, dialysis time,			
KPD wait list time, geographical proximity and HLA matching			
Limitations as per available resources are			
Use short (2- or 3-way) vs long chain to avoid logistic problems			
Manual allocation by a nephrologist supervised by ethical review board ensuring equitable			
allocation			

#### Group B. International guidelines for GFR for kidney donors and its validity for India

**Dr. Sandeep Mahajan**, Dr. Edwin Fernanado, Dr. K. Thirumurthi, Dr. Sanjeev Nair, Dr. Sukanto Barai and Dr. Arpita Lahiri

The consensus of this group -

- Recommend expressing kidney function as glomerular filtration rate (GFR) and NOT as serum creatinine concentration.
- Recommend expressing GFR in mL/min/ 1.73 m<sup>2</sup> rather than mL/min

• Recommend initial evaluation of GFR (screening) using estimated GFR from serum creatinine concentration (eGFRcr).

• Recommend that serum creatinine be measured using an assay standardized to the international reference standard. (1B).

• Recommend that eGFRcr should be computed using the 2009 CKD- EPI creatinine equation

• Recommend in all confirmation of GFR by a clearance technique like slope intercept method for DTPA GFR estimation (mGFR) and not estimated GFR with Techniques like Gate's method.

• Suggestion that following lower cut-off of GFRs should be used in patients who have no other comorbid illness that increases risk of CKD (as per table).

Age	Proposed Minimum GFR	British transplant society
20	100	80
30	90	80
40	80	80
46	74	80
50	70	77
60	60	68
70	50	59

Proposed GFR cut-offs (ml/min/1.73 m<sup>2</sup>)

- All efforts should be made to do spilt function along with the mGFR by the nuclear methods
- In case there is no contraindication to donation better functioning kidney should be left with donor

#### Group C - Contra-indications to deceased donations for South Asia Region

Authors : **Dr. Ravi Mohanka**, Dr. Noble Gracious, Dr A. Olithselavn, Dr. B. Subba Rao and Dr. Ruth Hardstaff

#### Tumors

Tumors in donors should be classified as per WHO guidelines to estimate the risk of transmission to the recipient into the following:

Absolute contra-	Primary cerebral lymphoma			
indication	All secondary intracranial tumours			
	<ul> <li>Active cancer with spread outside the organ of origin</li> </ul>			
	<ul> <li>Active cancer with spread outside the organ of origin</li> <li>Active haematological malignancy</li> </ul>			
High risk (>10%)				
	<ul> <li>Melanoma: without spread (except as below)</li> <li>Breast: cancer other than those identified below</li> </ul>			
	Kidney: renal cell cancer >7cm or stages 2-6			
	Sarcoma: >5 years previously and resected			
	Small cell cancer: lung/neuroendocrine			
	Lung cancer: stage I to IV			
Intermediate risk	Glioblastoma			
(between 2% and	Giant cell glioblastoma			
10%)	Gliosarcoma			
	Pineoblastoma			
	Medulloblastoma			
	CNS primitive neuroectodermal tumour			
	Medulloepithelioma			
	Ependymoblastoma			
	Atypical teratoid/rhabdoid tumour			
	Malignant peripheral nerve sheath tumour			
	Germinoma			
	Immature teratoma			
	Teratoma with malignant transformation			
	Yolk sac tumour			
	Embryonal carcinoma			
	Choriocarcinoma			
Low risk (between	Melanoma: superficial spreading type with tumour thickness <1.5mm with			
0.1% and 2%)	curative surgery and cancer free period of >5 years			
	• Breast: stage 1, hormone receptor negative with curative surgery and cancer-			
	free period of > 5 years			
	<ul> <li>Ovary: curative surgery and cancer-free &gt;10 years</li> </ul>			
	• Colon: adenocarcinoma with curative surgery and cancer-free period of >5			
	years			
	Thyroid: solitary papillary carcinoma 0.5-2.0cm			
	Thyroid: minimally invasive follicular carcinoma 1.0-2.0 cm			
	• Kidney: resected solitary renal cell carcinoma >1.0cm and <2.5 cm and			
	Fuhrman grade 1/2			
	Prostate: Gleason >6			
	Treated gastrointestinal stromal cancers			

Minimal risk	Skin: basal cell carcinoma	
(<0.1%).	Skin: squamous cell carcinoma with no metastases	
	Skin: non-melanoma skin cancer in situ	
	Uterine Cervix: in situ cancer	
	Thyroid: solitary papillary carcinoma (<0.5cm)	
	Thyroid: minimally invasive follicular carcinoma (<1.0cm)	
	Bladder: superficial non-invasive papillary carcinoma	
	• Kidney: Resected solitary renal cell carcinoma <1.0cm and Fuhrman grade 1/2	
	• Prostate: Gleason <6 or >6 with curative treatment and cancer free >3 years.	

- The risk of transmission of hormonal tumors to opposite gender) was not clear in the literature (e.g. donor with breast cancer to a male recipient OR donor with prostate cancer to a female recipient). Such donations may be accepted in view of low risk of transmission if the transplant team, the patient and their family feels that the risk of transmission is acceptable.
- The risk of transmission of donor tumors should be discussed with the recipient and their families by the transplant team, documented and a copy of the consent including all details should be submitted to the organ allocating authority for records.

#### Infections

- Infections in donors may often be undiagnosed or culture reports may be reported at a later date. The transplant team should obtain a copy of all culture reports from the donor hospital with the organ. Pending reports should be sent / collected once available. Donor blood / urine and other samples should be carried in appropriate media by the transplant team for culture at their own hospital with the organ.
- In case of a known infection in the donor, the nature of bacteria, extent of infection and susceptibility to antimicrobials should guide the organ selection. The transplant team should be very cautious in using organs from donors with multi-drug resistant (MDR) infections causing septic shock or multi-organ failure. The risk of a suspected or known infection in the donor and the risk of transmission should be weighed against the patient's condition and the same discussed with the recipient and family, documented and a copy of the consent submitted to the organ allocating authority for records.
- Donors are not routinely screened for rare infections such as Chagas disease, lymphocytic choriomeningitis virus (LCVM), Mycobacterium tuberculosis, Rabies, West Nile virus (WNV) and others, although the risk of transmission and of mortality is high with transmission of these infections. The same should be part of the consent process in all transplants.
- Some donor derived infections may not manifest early after transplant or the tests may be negative despite the infection because of the "window period", therefore donor blood and

plasma should be preserved for future testing. The recipient may be tested for the suspected infection at specified intervals (1 month, 3 months, 6 months, 1 year) as appropriate.

- Suggested donor's medical history to be recorded to determine risk of infection transmission is:
  - Medical history
  - Previous infections
  - Vaccinations
  - Occupational exposures
  - Travel history
  - o Transfusions with blood or blood products
  - Any contact with people with HIV, HBV, HCV or other transmissible diseases
  - Tattooing, ear piercing or body piercing
  - Use of illicit drugs
  - Sexual behavior
  - o Incarceration
  - Contact with bats, stray dogs or rodents (including pets)
- Routine infection screen suggested for all donors is:
  - o HIV antibody
  - HBV serology, including HBsAg, HBV core antibody and surface antibody
  - In HBsAg-positive donors: hepatitis delta virus antigen and/or antibody
  - HCV antibody
  - Nontreponemal and treponemal testing (RPR + TPHA or TPPA or FTA antibodies)
  - o HTLV-I/II) antibody (less common currently given assay performance)
  - Toxoplasma antibody (notably in cardiac donors)
  - Cytomegalovirus (CMV) antibody (IgG / IgM)
  - EBV antibody panel (EBV capsid antigen, with or without early antigen and nuclear antigen antibody levels)
  - Herpes simplex virus antibody
  - Varicella zoster virus antibody
  - Blood and urine cultures
- From the above screening, if an infection such as CMV is positive, it should be prevented in the recipient with appropriate anti-microbials. Organs from donors with infections such as HIV, HBV and HCV may be used for recipients with the similar / same infections if found suitable by the transplant team with plan for continued treatment of the infection in the recipient.
- We could follow the CNT / European risk classification system for infections as below:
  - **Unacceptable risk:** Includes absolute contraindication, some of the examples being
    - Definite, probable or possible case of human transmissible spongiform encephalopathy (TSE), including CJD and vCJD, individuals whose blood relatives have had familial CJD, other neurodegenerative diseases associated with infectious agents
    - TB: active and untreated
    - West Nile Virus (WNV) infection

- HIV disease (but not HIV infection)
- A history of infection with Ebola virus
- **Increased but acceptable risk:** Includes cases where transmissible organisms or diseases are identified during the evaluation process of the donor, but organ utilization is justified by the specific health situation of the recipient or the severity of their clinical condition.
- Calculated risk: includes all cases where, even in the presence of transmissible diseases, transplantation is allowed for recipients with the same disease or with a protective serological status; this risk applies also to donors with documented bacteremia and/or bacterial meningitis provided that the donor was on targeted antimicrobial treatment for a minimum duration of 24–48 h.
- **Not assessable risk:** includes cases where the evaluation process does not allow an appropriate risk assessment for transmissible diseases.
- **Standard risk:** includes cases where the evaluation process did not identify a transmissible disease.
- It was felt that TB should not be a contraindication for donation, because if its indolent nature and availability of effective AKT
- In India, other infections such as Dengue, Leptospira and others may be common and should be tested for when clinically suspected. Although few successful cases have been reported with Dengue, the transplant team should make the decision based on the risk – benefit to the recipient.

#### Poisoning

In cases where poisoning is the cause of death, oragno-phosphorus and organo-chlorous poisoning can cause brain death and would be suitable organ donors. Snake bite, which is also very common in India, can cause hemolysis, DIC and may cause ATN, in which case, the kidneys may not be usable, however, other organs can be used (Reference).

#### Organ specific contraindications

Specific contraindications for liver donation

- Acute hepatitis of viral, drug or other known aetiology
- Serum AST or ALT > 10000 IU/L (if of liver origin)
- Cirrhosis / Fibrosis (> 3)
- Portal vein thrombosis
- Metabolic diseases that would be of harm to the recipient and not treatable (such as haemophilia A and B, inborn errors of metabolism such as oxaluria, tyrosinaemia)
- Fatty Liver > 60%

Specific contraindications for Small Bowel donation

• DCD donors

- DBD donor age  $\geq$  56 years or weight of 80 kg or more
- Underlying chronic intestinal disease
- Intra-abdominal sepsis
- For abdominal wall / fascia donation: Extensive surgical scars/damage to the abdominal wall/fascia

Specific contraindications for kidney donation

- Chronic kidney disease (CKD stage 3B or worse, eGFR < 45 consider Dual, < 30 CI)
- AKI (?) Etiology, previous renal function
- Long term dialysis (that is, not acute relating to acute illness)
- Renal malignancy: Prior kidney tumours of low grade and previously excised would not necessarily exclude donation
- Previous kidney transplant (> 6 months previously)
- Chronic kidney disease (CKD stage 3B or worse, eGFR < 45 consider Dual, < 30 Cl)
- AKI (?) Etiology, previous renal function
- Long term dialysis (that is, not acute relating to acute illness)
- Renal malignancy: Prior kidney tumours of low grade and previously excised would not necessarily exclude donation
- Previous kidney transplant (> 6 months previously)

Specific contraindications for pancreas donation

- Insulin dependent diabetes (excluding ICU associated insulin requirement)
- Non-insulin dependent diabetes (Type 2)
- Any history of pancreatic malignancy
- Donor BMI > 40 kg/m2
- Donors <15 kg (except where there is a small paediatric IFALD patient who requires donation of a pancreas with other abdominal organs)
- DBD donors  $\geq$  66 years
- DCD donors aged ≥56 years

Specific contraindications for heart donation

- Urgent:
  - Age of 65 years or more
- Non-urgent:
  - Documented coronary artery disease (e.g. confirmed history of MI, CABG or percutaneous stenting)
  - Median sternotomy for cardiac surgery
  - LVEF  $\leq$  30% on more than one occasion
  - Massive inotropic or pressor support, but only if adequate circulating volume has been confirmed by monitoring

Specific contraindications for lungs donation

- DCD donor age > 65 years
- DBD donor age >70 years
- Previous intra-thoracic malignancy
- Significant, chronic destructive or suppurative lung disease (those with controlled asthma are suitable donors)
- Chest X-ray evidence of major pulmonary consolidation

## Group D. ATT in Prospective Kidney Recipient - New thoughts and recommendations for Indian Patients

Authors - Dr. Santosh Varughese, Dr. Chakko Korula Jacob, Dr. Debabrata Mukherjee, Dr. Subramanian S, Dr. Suresh D and Dr. Vinoi George David

The discussion regarding pre-transplant anti-tubercular therapy discussion came to the following conclusions (based on currently available evidence and existing clinical practice)

The following concerns were discussed and the following suggestions were recommended:

#### 1. Duration of pre-transplant anti-tubercular therapy

The available data regarding anti-tuberular therapy is 6 to 9 months (Western); 9 to 12 months (Pakistan) and 18 months (India).

Most data suggests use of Isoniazid, Ripampicin (or Oflaxicin), Ethambutol and Pyrazinamide based regimes. Isoniazid and Rifampicin do not require dose modification in dialysis patients, whereas Ofloxacin, Pyrazinamide and Ethambutol require dose modification.

Rifampicin in the post-transplant period causes a decrease in trough levels and resulting in increase in the dosage requirements of calcineurin inhibitors, increased costs, increased costs, increased risk of rejections (25%-35%), increased risk of graft loss (27%) and mortality risk by 5-fold or 56%.

#### The following were our suggestions:

- a) All prospective transplant recipients diagnosed to have tuberculosis should receive treatment before transplant
- b) The **intensive** treatment options could be:

2 months of Isoniazid, Rifampicin, Ethambutol and Pyrazinamide or

3 months of Isoniazid, Ofloxacin, Ethambutol and Pyrazinamide

c) The **maintenance** treatment could be:

4 months of Isoniazid, Rifampicin (if the Intensive treatment included Rifampicin)

12 months of Isoniazid, Ethambutol  $\pm$  Ofloxacin (if the Intensive treatment excluded Rifampicin)

It is expected that the latter will be preferred when the immunosuppressive regimen includes a Calcineurin Inhibitor

#### d) Recommendation

i) Best result if patient completes full course before renal transplant

ii) Recommended that the minimum time renal transplant to be covered is 8 weeks if there is "inability to continue" on the part of the patient (medical, social, financial reasons, etc),

#### 2. Has anything changed over the years with regard to pre-transplant tuberculosis?

- a) There has been an increase in drug resistance to anti-tubercular therapy including community acquired multi-drug resistance.
- b) Diagnostics of tuberculosis have improved with newer culture techniques and Gene Xpert PCR
- c) Rifabutin is an option (in place of Rifampicin) in view of lesser enzyme induction (consequently lesser reduction in calcineurin inhibitor exposure), similar efficacy and more active than Rifampicin against Mycobacterium buberculosis. The dosage is also similar - 5mg/kg (maximum 300mg/day)

#### 3. <u>Should "latent tuberculosis" be treated? (Hitherto called "INH prophylaxis")</u>

Isoniazid prophylaxis in all 3 studies in South Asia showed decreased risk of developing posttransplant tuberculosis (RR 0.35; 95% Cl 0.14 to 0.89) with no beneficial effect on all-cause mortality (RR 1.39; 95% Cl 0.70 to 2.78). However there was substantial risk of liver damage (3 studies, RR 2.74, 95% Cl 1.22 to 6.17). Up to 22.8% may develop hepatotoxicity and as many as 25% of these may die of hepatic failure.

#### The following were our suggestions:

- a) Empiric Isoniazid to all transplant recipients is NOT advisable
- b) Despite lower incidence of tuberculosis with Isoniazid, the absence of any survival benefit, increased hepatotoxicity with Isoniazid and possibility of adding to Isoniazid resistance, empirical Isoniazid administration indiscriminately to all is not to be done.
- 4. <u>Should "secondary Isoniazid prophylaxis" be given to recipients with past completely treated</u> <u>tuberculosis and those receiving organs from donors with past tuberculosis?</u>
  - a) Recipients with past completely treated tuberculosis should not be given Isoniazid prophylaxis there was no consensus and more discussion is needed
  - b) In organs from donors with past completely treated tuberculosis, the likelihood of transmission is very low and the number needed to treat is very high, therefore the recommendation is NOT to give Isoniazid prophylaxis.
- 5. <u>How should Multi-Drug Resistant (resistant to Isoniazid and Rifampicin) and eXtremely Drug</u> <u>Resistant (resistant to Isoniazid, Rifampicin, Fluoroquinolone and 1 injectable drug [Amikacin / Kanamycin / Capreomycin]) mycobacterial infections be treated?</u>
  - a) The diagnosis of MDR / XDR tuberculosis must be always be made with mycobacterial culture and sensitivity.

- b) The treatment must never be empiric.
- c) Additional consultations with Infectious Diseases specialists must be undertaken especially before injectable drug/s is/are introduced.
- d) Never add a single new drug to a failed ATT regimen as it is likely to result in inadequate or under-dosing of therapy.

#### **Group E. Induction Protocols for India**

#### Lead - Dr. Manish Rathi, Chandigarh

Members:

- Dr. Rajan Ravichandra Chennai
- Dr. Shyam Bansal New Delhi
- Dr. Sreejith Parameswara Puducherry
- Dr. Sandeep Aggarwal Delhi
- Dr. C. N. Srinivas Chennai

Awaited from Dr. Manish Rathi

#### Group F. Amsterdam/KDIGO Guidelines - Modifications for India

**Lead - Dr. Georgi Abraham,** Dr. Rajeevalochana Parthasarathy, Dr Ashish Sharma, Dr. Amresh Krishnan, Dr Umesh oza, Dr S. Sundar and Dr Sunil Shroff

With the ever-increasing burden of end stage renal disease (ESRD) renal outcomes of the living donors have gained importance. Traditionally, living donors have been selected on the basis of an absence of risk factors for poor outcomes after donation and without a comprehensive assessment of individualized long-term risk. Although kidney donation is considered to be safe in healthy, low-risk persons, donation has lifelong implications, and the most direct effect may be an increased long-term risk of ESRD. [1,2,3,4]

At the midterm ISOT meet held in March 2017, we discussed the living donor guidelines to be tailored to the Indian perspective. The following suggestions were made by the group members after a brief presentation on the existing living donor guidelines. (KDIGO 2015(5), ERBP 2013(6), CARI 2010(7), Amsterdam forum(8) and UNOS 2013(9) BTS 2011 [10])

The following aspects were discussed:

- 1. Living donors with impaired fasting glucose
- 2. Potential donors with hypertension
- 3. Hypertension
- 4. Proteinuria
- 5. Donor BMI
- 6. Age

- 7. Donor insurance and follow up
- 8. Laproscopic versus open donor nephrectomy
- 9. Donor infections
- 10. Cancer screening

#### 1. Living donors with impaired glucose tolerance

It was agreed that Diabetes mellitus is an absolute contraindication for donation. (Fasting blood glucose > 126 mg/dl on 2 occasions) [5,6,7,8,9] Patients with an impaired glucose tolerance should have an oral glucose tolerance test performed[10]

#### Suggestions made in the meeting were

- Impaired glucose tolerance with persistant microalbuminuria should be contraindication
- Gestational DM should be considered a contraindication
- Strong family history and younger person with negative OGTT Counsel thoroughly on the future risks of kidney donation.

#### 2. <u>Hypertension</u>

Donors should have a BP<140/90 on 3 separate occasions [5,6,7] Donors with BP>140/90 with end organ damage should be considered a contraindication for donation.

The indications for Ambulatory blood pressure monitoring in potential donors given by various guidelines include older donors[8] and White coat hypertension[7]

#### Suggestions made in the meeting were:

#### Indications for Ambulatory blood pressure monitoring

- Newly diagnosed Hypertensives
- Uncontrolled Hypertensives on less than 2 drugs

#### 3. Proteinuria and microalbuminuria

It was agreed that proteinuria>300 mg/24 hours or a spot Urine Albumin-to-Creatinine Ratio (UACR) >300 mg/g should be considered a contraindication to donation .[6,8] Microalbuminuria is a relative contraindication to donation[10]

#### Suggestions made in the meeting were

• Microalbuminuria : In view of the increasing prevalence of DM in India , 24 hour urine protein between 150-200 mg/dl will be considered as microalbuminuria

#### 4. <u>BMI</u>

BMI more than 35 kg/m<sup>2</sup> is a relative contraindication to donation[8,10] and ethnicity, risk factors and cardiac risk factors[10] should be carefully considered.

#### The suggestions made at the meeting were:

- BMI >35, well informed consent to be taken since no evidence from India
- 30-35- To encourage weight loss prior to donation
- Co morbid conditions and a BMI of >35 should be considered a contraindication to donation.

#### 5. Donor nephrectomy

Methods of donor nephrectomy should be individualized [6,7,10] and minimally invasive techniques may be preferred form of kidney removal

#### The suggestions made at the meeting were:

Minimally invasive methods preferable in the center where there is available expertise especially for left donor nephrectomy; however currently this cannot be considered as standard of care.

#### 6. Infections

Active HIV, Hepatitis B and C have been considered a considered a contraindication to transplant and the list of infections to be tested for varies among different guidelines.[6,8,9,10] In the meeting suggestions made were:

Infection testing should be individualized in India as currently there are no set guidelines on an Indian perspective.

No consensus guidelines was derived.

#### 7. Donor Insurance and Follow up

#### The following suggestions were made at the meeting

- Donor insurance Advising health insurance for donors for long term follow up.
- Donor Follow up: Suggested 1 visit after 3 months after that yearly.
- Urine exam, sugars, BP, Serum creatinine should be used as standard tool for follow up.

#### 8. Informed consent

#### The following suggestions were made:

- Detailed Informed consent both by the surgical and medical teams.
- Individualised in gray areas like obesity, hypertension or impaired glucose tolerance (IGT).
- HLA typing as per legal requirement of the law of the country.

#### 9. Donors needing transplant

#### The following suggestions were made:

• National registry in conjunction with the ISOT should maintain such a list.

• Priority should be given in organ allocation by all organ distribution networks to such indivisuals.

#### 10. Nephrolithiasis:

It was felt that the suggestions made in the Amsterdam Forum[8] can be followed with special emphasis on ruling out cystinuria and hyperoxaluria. In suspicious cases rule out cystinuria and hyperoxaluria ( to be elaborated)

#### 11. Malignancies:

Centers must develop protocols consistent with cancer societies, and once developed follow their own protocols for screening for following cancers:[9]

- Cervical Cancer
- Breast Cancer
- Prostate Cancer 
   Colon Cancer
- Skin Cancer
- Lung cancer

This is a summary of all the suggestions given for forming living donor guidelines suitable from an Indian perspective. Further detailed evidence based guidelines are required including long term donor follow up to be put forth based on Indian data to safeguard and protect living donors

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#### Roundtable discussion for Transplant Coordinators Group A. Guidelines for setting up of Deceased Donation in Hospitals Speaker: Mrs. Jaya Jairam Chairpersons: Dr. S. Soundararajan and Ms. Arati Gokhale

Following persons participated in Group discussion on the subject matter -

#### Lead: Mrs. Lalitha Raghuram Members :

- Dr. Vijayanand Palaniswamy Mr. Sudhir Dewan
- Dr. Ravi Wankhede Mrs. Deepika Arora
- Mr. P Jain Ms. Jeena
- Mrs. Vijayamma Harikrishnan Dr. Harikrishnan
- Mr. Subroto Sahu
   Mrs. Jaya Jairam

Following Guidelines were arrived at -

- 1. Legalities & Training
- 2. Standardization of Procedures
- 3. Sensitization

#### Legalities & Training

- 1. Infrastructure to be in place :
  - a. Ensure Tx Team in place & have weekly meetings
  - b. BD Committee in place including one member from empaneled list
  - c. Dialysis center, well equipped twin OT & ICU to be on the same floor
  - d. Trained TC with Training certificate
  - e. Panel members to be identified and in place
  - f. Blood Storage facilities with MOU for supply of Blood or In house blood bank
  - g. Have Lab facilities in place

- h. Have facilities & expertise for packing & dispatching
- 2. Form 12 to be filled and submitted to appropriate authority DHS / DME along with fees for application. All necessary enclosures to be enclosed with Form 12 for every organ
- 3. Expect 3-member inspection team and satisfy the inspector's queries
- 4. License is obtained for 5 years & subsequently renewable (3 months before expiry)
- 5. Ensure all other statutory licenses in place prior to Tx license application
- 6. Conduct Mock drill / Dry Run
- 7. Enroll with State Allocating body with fees, if any and patients should be registered with Hospital as well as with State Registry.
- 8. Budget the cost to patient with inclusions & exclusions with riders

#### SOPs

- 1. Lay down detailed SOPs for BD identification & next response actions including -
  - Each Team member's roles & responsibilities to be clearly laid out
  - MLC cases, Grief counseling, Obtaining consent, Respectful handing over of body
- 2. Laminate SOPs & display in the nursing station for easy accessibility

#### **Sensitization Efforts**

INTERNAL:-

- Level 1 training Identify nurses in ICUs, Emergency dept, OT
- Level 2 training Outside nurses, Housekeeping staff, etc
- Intense sensitization for doctors, ICU team, neurosurgeon, intensivists, other key stakeholders
- Subtle Branding within the hospital
  - Kiosk in reception with handouts & display
  - Display materials in waiting areas, corridors etc posters, banners, standees
  - Close circuit TV to display messages

#### EXTERNAL :-

- Entire Tx team to be involved in monthly awareness activities during -
  - World Liver day
  - World Kidney day
  - Founder Day, etc
  - Have the Doctors & Staff Pledge and make it a media event
  - Local Police awareness

#### Group 2 - Setting up an organ retrieval program in NTORC

#### Lead: Mr. Aneesh P. V.

Chairpersons: Dr. S. Soundararajan and Ms. Arati Gokhale

Members:

Trilly Mathew

Sunayana Singh

Arati Gokhale

Surekha Joshi	Aneka Paul	Muneet Sahi,
Sharmila Padhye	Urmilla Mahajan	Hemlata Shah
Kavitha Aneesh	Bhanuchandra	Bhanu Prakash
V. G. Prasad	Vinod Kumar	Hemlata Singh Parmar

#### **Need of NTORC**

- Huge gap between demand and supply
- Many of the RTA cases are taken to the local hospitals
- Would lead to increase the deceased donation
- May help reduce the commercial dealing

#### Recommendations

- Identifying the NTORCs
- Expenses during the donation should be taken by the recipient hospitals
- CME and CNE to be done regularly
- Empanelling of more doctors for certification

#### Guidelines by the group

- BD declaration shall be mandatory Government should issue an order in this regard. Government body should identify the doctors for BD declaration.
- SOTTO/ROTTO/NOTTO should identify the NTORC and give them registrations rather tell them to register.
- NTORC will not have the full time Tx Coordinator, so ideally SOTTO/ROTTO/NOTTO shall have one coordinator to facilitate the donation.
- If organs are not viable/usable SOTTO/ROTTO/NOTTO can have some funds to bear the loss faced by NTORC.
- CME, CNE and Public awareness on organ donation, Awareness posters
- Donor maintenance and retrieval charges should be shared by the retrieval hospitals.

#### Day 3 – 18 March 2017, Afternoon Session

#### Lunch Symposium – De novo use of "OD Tacrolimus" – The Bangalore Experience Speakers: Dr. S. Sundar & Dr. Sanjay Srinivasa Chairpersons: Dr. Chacko Jacob & Dr. R. K. Sharma

Conventional Tacrolimus is formulated for immediate release and is available for absorption till proximal small bowel, while Once daily Tacrolimus is a prolonged release formulation of Tacrolimus available for absorption even at distal small bowel and Ascending colon.

They spoke on their experience in terms of use of BD TAC / OD Tac, combination of steroid, immunosuppressant medicines that they are prescribing. They said that the OD Tacrolimus was

introduced to improve drug compliance and inter and intra subject variability. He quoted a study where nearly 45% of recipients have failure of graft due to non-adherence. He also highlighted that the benefits to the patient with improved renal function and decreased side effects. The same effects are seen when transplant recipients are converted from Tac BID to Tac OD.

In conclusion -

- Advagraf provides similar efficacy and safety profiles to Prograf
  - evidence of better renal function
- easy conversion and effective de novo patient management
- lower intra- and inter-patient variability
- simplified and more convenient dosing regimen
- opportunity for Advagraf monotherapy
- potential advantages for adherence and long-term outcomes may become evident with longer follow-up

#### END OF LIFE CARE AND ORGAN DONATION

#### A. Uniform Declaration of Death

Speaker: Dr. Sunil Shroff

#### Chairpersons: Dr. Umesh Oza & Dr. Vijayanand Palaniswamy

Dr. Shroff took the audience through the definition and recognition of death over the ages. He said that Brain Death was not invented for Organ donation. He said that technology has made death very complex : You don't need heart to be kept alive (Thanks to the Ventricular assist devices): You don't need lungs to be kept alive (Thanks to ECMO).

There is an urgent need to break the link between Brain death and Organ Donation. The reasons for poor brain death diagnosis are –

- Trust in Doctors is missing
- Doctors fear that Hospital reputation may be at stake if brain death is declared
- In the event of Brain death, Language used by doctors such as "Kept alive" for Organ donation is wrong
- Brain Death certificate is not accepted for cremation, death register, police, etc.

He urged that the doctors should work together to get India to have a uniform declaration of death like US Act. In case of organ donation after circulatory death, India allows Maastricht Criteria 4 (Controlled) patients to become donors.

**B.** End of Life care legislation in the context of enabling DCD in India Speaker: Dr. R. K. Mani Chairpersons: Dr. Umesh Oza and Dr. Vijayanand Palaniswamy Dr. R. K. Mani explained the dead donor rule and how this has shown an effect on the increased numbers of DCD in the US. Live donations in US are only 0.5% whereas here it is > 95%. He said that studies in Netherland have shown that with increase in DCD the number of donations from DBD have decreased. He listed the principles governing deceased donor organ transplantation, like obtaining consent, palliative care, death determination teams etc. He gave an example of Unified Operational Definition of Death as:

## "the permanent loss of capacity for consciousness and all brainstem functions, as a consequence of permanent cessation of circulation or catastrophic brain injury"

He said the role of medicine is not only restoring health and extending life, but also to relieve pain and suffering. The lack of awareness, knowledge and training in bioethics and terminal care inhibits the doctors to take decision in EOL care. He explained the DNR order and explained the role of meticulous documentation in supporting the decisions. In India DNR is not allowed, The MCI code of Ethics says that practicing euthanasia is unethical. On the other hand the Government of India is proposing a Draft bill called the Terminally III Patients Bill to define end of life care issues.

In his concluding statements he said that India needs to

- Inform policy makers of expanding donor pool through developing a DCD protocol for India
- Advocacy for contemporary EOL care policy crucial for DCD
- Must move away from live donor to cadaveric donations
- Must integrate contemporary ethical principles into new reforms

# **C.** Ethical Dilemmas in EOL Care in handling potential Brain dead donors in ICUs Speaker: Sujatha Suriyamoorthi

Chairpersons: Dr. N. Sridhar & Dr. V. Ponniah

She started with listing the main dilemmas in EOL care decision making, from patient's preferences, family preferences and ability of the patient family to understand the patient's choice. She described different instances though case studies.

Case studies with respect to Ethical Dilemmas were presented -

- In one case, the patient was found brain dead and after counselling, the family consented to donate the organs of their loved one. But later, organs were found unfit for donation and subsequently; the doctor did not proceed with brain dead declaration and remove the ventilator. Dilemma Dead enough for donation but not dead enough for taking off the ventilator?
- In another case, the patient was found to be brain dead and upon counselling, the family did not consent to donation. Should the patient be continued to be kept on ventilator? Dilemma Doing Good Vs. Justice
- In another case, family kept asking for more time to decide on consenting to organ donation; however it was a race against time. Dilemma Giving time to Family Vs. Efficiency

She concluded by saying that:

- Uniform guidelines are the need of the hour
- Organ donation should not be inflicted
- Discussions on Organ donation should be part of EOL care

**D.** EOLC Legislation in India Speaker: Dr. Roop Gursahani Chairpersons: Dr. N. Sridhar & Dr. V. Ponniah

He started by tracing the growth of medicine such that seriously ill patients returned home after recovering from their illnesses. In US the hospital started asking the patients for living wills and their decisions in EOL care. In 1980s the concept of patient's autonomy took root and the modern principles of medical ethics were accepted world over. He explained a study wherein the Quality of Death was studied and India came in the bottom 40 countries. Unless we increase our spending in health, this sad situation shall continue.

He believed that there seems to be a feeling amongst most of us, especially the Indian elite that the rest of us are somehow different. He felt that the lawmakers and the decision makers feel that our fellow Indians cannot be trusted with autonomy and this is one of the barriers to effective EOL Care. Change in Public attitudes is very important

He said that we need to have EOLC Law and not guidelines; build professional capability; very important that issues should be resolved within the Medical Community and have a uniform declaration of death in place.

#### DETECT AND PROTECT

#### **A.** Safety & Ethical issues in Living Donations Speaker: Dr. N. Gopalakrishnan Chairperson: Dr. Rajan Ravichandran

Dr. N. Gopalakrishnan outlined the immediate and long-term complications / safety of kidney donations and, the gender bias and 'vulnerability' within the framework of related donors while explaining the ethical issues.

The immediate complications of live kidney donation have been Post-operative morbidity, pain and hospitalisation. Mortality even though very rare and Loss of 'work days' affect the patient and the family. Some of the long term complications that he stated were overall survival, Proteinuria, Hypertension, Renal failure and cardiovascular morbidity & mortality.

Studied have shown that in living donation women form a major pool of the living donors while there percentage in terms of being a recipient is very less. In terms of deceased donor transplant females constituted 19% as the donors and 29% as recipients of a deceased donor organ.

When it comes to directed donation to a loved one, intense emotional pressure and covert coercion is involved on the reluctant donor.

According to a study on Psychosocial assessment of Kidney Donors by Suguna Rajendran, Madras Medical College, JAPI, 1999: 96% of the donors were unaware of the option of organ donation, 87% initially objected, half of them donated primarily due to emotional reasons, 44% of them feared surgery and the inability to work after it and 22% of the them donated expecting some kind of incentive.

Dr. N. Gopalakrishnan concluded the session by saying that no compromise should be made in donor selection, one needs to look into if single - drug hypertensive donor is all right, ensure periodic donor evaluation, starting of a Kidney donor registry, vigorous pre-donation education and ensure that all the potential long-term risks are informed to the donor. In the end he wished that one should promote deceased donor renal transplantation which meant no risk on any donor.

#### **B.** Interview of donor and recipient Speaker: Mr. J. Nethaji, Chennai Chairperson: Dr. Rajan Ravichandran

He said that though organ donation by living donors clearly saves lives, in case of living donation women donors are significantly higher than men (OPTN, 2006). There are many moral dilemmas surrounding the same. Emotional and societal pressures are major drives in living donation.

He explained that the donor interview should address the following issues – if the donor is eligible or not, make the donor understand the policies, process and procedures of the transplantation, the time and money involved in the same, identifying a caretaker for the donor and ensuring there has been no pressure on the donor to make the decision to donate.

For the recipient we need to ensure the recipient understands the benefits of transplantation, possible outcomes, he needs to be on lifelong medications, there might be chances of rejection and Side effects. One also needs to ensure that the recipient has the capacity to understand the problem, complies with drug and abstains from alcohol.

He also added that a transplant coordinator is a Donor's Advocate and he must convey to the donor that it is normal to be afraid of donating but also feel guilt about not wanting to be a donor. TC must ensure that donors should not, under any circumstances, feels pressurized to donate. Potential donors are encouraged to ask more questions or concerns about their decision. Finally the "RIGHT" decision is the one that makes the Donor feel comfortable - Donor's motivation to donate. Inabilities to bear the suffering of a loved one or Emotional pressure by family, in-laws or society or Financial benefits are usually the main reason to donate.

#### C. Identifying Discrepancies in Documents and Lessons Learnt Through Recent Cases

#### Speaker: **Ms. Trilly Mathew** Chairperson: **Dr. Rajan Ravichandran**

Trilly shared her experience as a transplant coordinator and emphasized that Transplant Coordinator (TC) has to play the role of an Investigator while dealing with living donation. The TC must assess the motivation behind the donation. Thorough Interrogating, Preparing a family tree, verifying the documents and Advising DNA test in case of doubt are a must to ensure that there are no loopholes in a case of living donation.

Trilly shared many cases that she herself dealt with and figured out that the cases were fake and not genuine. The Lessons Learnt and shared by her were that Documents are man-made but DNA can never go wrong. HLA matching is not always trustworthy. A TC must always play the DEVIL's 'ADVOCATE' and evaluate each case with an eagle eye. She concluded by saying that a TC is a 'GUARDIAN' of the law and has a big responsibility to save the reputation and image of the hospital, department, doctor, self and most importantly the cause of organ donation. So one must play it well

#### **D.** Psychological evaluations Speaker: Ms. A. Radhika Inuganti

### Chairperson: **Dr. Rajan Ravichandran**

Ms. Radhika said that as a psychologist, she looks at how to support the patient and family through the process of transplant and so early identification of contraindications will help to prepare the patient and family.

In cases of organ transplantation, there has been an association between Axis I disorders which are the major DSM Disorders Adjustment Disorders, anxiety disorders, etc and poorer psychosocial adjustment and health status, while Axis II diagnoses which is related to personality and intellectual disabilities were associated with poorer compliance.

There are some standard tools to assess the patient -

PACT - Psychosocial Assessment of Candidates for Transplant

PLS - Psychosocial levels system

TERS - Transplant Evaluation Rating Scale

Some organ specific tools also exist - SIPAT - Stanford Integrated Psychosocial Assessment Tool She then explained in details the four domains of SIPAT -

Patient's Readiness Level

Social Support System

Psychological Stability And Psychopathology

Lifestyle & Effect Of Substance Use

She described how the results after using the SIPAT Tool come as

Excellent Candidate

Good Candidate - List Risk Factor

Minimally Acceptable Candidate - Risk Factor To Be Addressed – Consider Listing

Poor Candidate – Deferral Recommended Until Risk Factors Are Addressed.

High Risk – Not Recommended While Risk Factors Exist e.g. Active Substance Use, Suicidal, Etc Also Lists Contraindications In High, Moderate And Low Risk, Absolute And Special Consideration

She said that there different methods to evaluate a donor. No standard tool has been developed as yet. There are efforts by United Network Of Organ Sharing, American Society Of Transplant Surgeons And American Society For Transplantation for the psychosocial evaluation of non relative kidney donors

#### E. Dealing with Foreigners

#### Speaker: Mr. K. Shankarganesh

#### Chairpersons: Dr. Rajan Ravichandran

Mr. Shankarganesh, described the work entailed in transplants for foreigners. He said that a lot of time should be given to counselling and evaluation of the patient. The documentation should be accurate, with all certificates and affidavits in place. He then explained the entire list of documents. He said that the patient should be well aware of all the legal formalities. He also shared how to deal with catastrophic happenings in a foreign land such as –

- A foreign patient dying before transplant or,
- A foreign patient dying after the transplant.

He spoke of the challenges encountered during his work as difference in cultures and working styles, medical visa durations, dealing with the anxiety of the patients and the family; he suggested that the transplant hospital should have a good rapport with the embassies so that there is always an option of reaching out to solve any issue.

End of Conference

### 18<sup>th</sup> March 2017



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