

ADVANCED TRANSPLANT COORDINATORS' WORKSHOP

23rd & 24th March 2018,
PRIDE Hotel, Chennai

LET US REFOCUS

PROCEEDINGS

Supported by

TATA TRUSTS

Organised by



MOHAN
FOUNDATION

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COORDINATORS' WORKSHOP
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www.mohanfoundation.org

Title:

PROCEEDINGS OF THE ADVANCED TRANSPLANT COORDINATORS'
WORKSHOP – LET US REFOCUS

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Contents

Foreword	1
Programme Schedule	2
Inauguration	4
Indian Transplant Newsletter	4
What is New in Each Centre - Nagpur Activities	5
Use of Social Media	6
Let Us Refocus – Feedback From The Team	7
Content Writing & Infographics	8
My Journey as a Marathoner	8
Donation after Circulatory Death	9
Experiences and Knowledge Sharing From Gift of Life Institute, USA	10
Organ Sharing Registry	11
E- Learning Module (Transplant coordinators’ training)	11
Photography- How to Take a Good Picture/ Video & When	12
How to Write a Good Press Release?	12
What Is New In Each Centre - Jaipur Activities	13
MOHAN Foundation and MoU with NHS Blood and Transplant, UK	13
Organ Donation Helpline App and Report	13
Memorandum of Understanding with NHS Blood and Transplant, UK	14

Innovative Activities in Advocacy Programme & Internship Programme	16
Innovative Activities in Training Programmes for transplant coordinators and ICU workshops	16
What Is New In Each Centre – Tamil Nadu Activities	17
What Is New In Each Centre – Chandigarh Activities	18
What Is New In Each Centre – Mumbai Activities	19
What Is New In Each Centre – Telangana Activities	19
What Is New In Each Centre – Delhi Activities	19
MOHAN USA	20
Multi- City Study of brain-stem death and counselling for organ donation in Government Hospitals	20
Why Is It Important To Do “Daily Reporting” – Award & Penalties	22
Way Forward	22

Foreword



The Advanced Transplant Coordinators Workshop stood out with its theme ‘Let us Refocus’.

An interesting perspective on Donation after Cardiac Death was shared by Dr. Darius Mirza from University Hospital Birmingham and Birmingham Children’s Hospital. Ms. Jayanthi Sampathkumar (via Skype) from Microsoft spoke about her journey as a marathoner in a saree which gave her a title in the Guinness Book of World Records. Also present via skype Dr. Satya Vrat Sharma, from Promoting Organ Donation (POD), UK and Dr. Anirban Bose, MOHAN USA pointed out the progress that NHSBT has made after signing the MoU with MOHAN Foundation, and the role of MOHAN USA and its accomplishments respectively.

MOHAN Foundation speakers highlighted the various projects being done by the Foundation and its strengths and weaknesses.

The workshop brought together MOHAN Foundation staff from Delhi, Mumbai, Nagpur, Hyderabad, Madurai, Salem, Coimbatore and Chennai. There was a display of photographs from different states of various activities done by the MOHAN Foundation team to spread the message of organ donation.

The proceedings of previous meetings as well as this one is available on our website - <http://www.mohanfoundation.org/proceedings/index.asp>

Dr. Sunil Shroff
Managing Trustee

Mrs. Lalitha Raghuram
Country Director

Programme Schedule
Friday – 23rd March 2018

Timing	Topic	Speaker
10.30 am – 10.40 am	Welcome and Prayer	Mrs. Lalitha Raghuram and Dr. Ravi Wankhede
10.40 am – 11.20 am	Indian Transplant Newsletter	Dr. Sumana Navin
11.20 am – 11.50 am	Nagpur activities – What is new?	Dr. Ravi Wankhede
11.50 am – 12.30 pm	Use of Social Media	Mr. Gowtham
12.30 pm – 1.00 pm	Welcome address	Dr. Sunil Shroff
1.00 pm – 1.30 pm	Let us Refocus – feedback from the team	Ms. Lalitha Raghuram
1.30 pm – 2.00 pm	Lunch	
2.00 pm – 2.30 pm	Content Writing & Info graphics	Ms. Thilaka Ravi & Ms. Amala
2.30 pm – 3.00 pm	My journey as a Marathoner	Ms. Jayanthi Sampathkumar
3.00 pm – 3.30 pm	Donation after circulatory death	Dr. Darius Mirza
3.20 pm – 3.40 pm	Experiences and knowledge Sharing from GOLI, USA.	Dr. Sumana Navin & Ms. Sujatha Suriyamoorthi
3.30 pm – 4.00 pm	Organ sharing registry	Mr. Suganya
4.00 pm – 4.30 pm	E- Learning Module (Transplant coordinators training)	Ms. Ann Alex
4.30 pm – 5.00 pm	Photography- How to take a good picture/ video & when	Mr. Siva Shankar
5.00 pm – 5.30 pm	How to write a good press release?	Ms. Pallavi Kumar
5.30 pm – 6.00 pm	Jaipur activities - What is new?	Mr. Prajesh Taneja
6.00 pm – 6.30 pm	MOHAN UK and MoU with NHSBT	Dr. Sunil Shroff
6.30 pm – 7.00 pm	Organ Donation Helpline app and report	Dr. Hemal Kanvinde
7.00 pm – 7.30 pm	MoU with NHSBT	Dr. Satya Vrat Sharma

Saturday – 24th March 2018

Timing	Topic	Speaker
8.30 am – 9.00 am	Innovative activities in advocacy program & Internship program	Dr. Hemal Kanvinde
9.00 am – 9.30 am	Innovative activities in training programmes for transplant coordinators and ICU workshops	Dr. Sridhar Nagaiyan & Dr. Sumana Navin
9.30 am – 10.30 am	Tamil Nadu activities – What is new?	Ms. Sujatha Suriyamoorthi Ms. Sunitha Velankanni Mr. Venkatesh Mr. Ragavan Mr. Raja Ms. Persis Mr. Nishanth Mr. Santhosh Kumar
10.30 am – 11.00 am	Chandigarh activities – What is new?	Mr. Sudhir Dewan
11.00 am – 11.30 am	Mumbai activities – What is new?	Mrs. Jaya Jairam & Mr. Amit Shenoy
11.30 am – 12.00 pm	Hyderabad activities – What is new?	Dr. Bhanu Chandra
12.00 pm – 12.30 pm	Delhi activities – What is new?	Ms. Pallavi Kumar
12.00 pm – 1.30 pm	MOHAN USA	Dr. Anirban Bose
1.30 pm – 2.00 pm	Lunch	
2.00 pm – 2.30 pm	Multi- city study of brain-stem death and counselling for organ donation in government hospitals	Dr. Sumana Navin
2.30 pm – 3.00 pm	Why is it important to do “Daily Reporting” - Award & Penalties	Mrs. Lalitha Raghuram
3.00 pm – 4.00 pm	Way forward	Dr. Sunil Shroff

DAY 1: 23rd March 2018

INAUGURATION

Dr. Ravi Wankhede began with an invocation song. Mrs. Lalitha Raghuram welcomed all the delegates present. Dr. Sunil Shroff, Managing Trustee in his welcome address said that this was the time for the MOHAN Foundation team to get to know one another and learn about the work being done in various states. He announced that the Government of Tamil Nadu has given permission to appoint transplant coordinators in all the Government hospitals. The focus of the meeting was to hear the views, needs of the coordinators and how everyone can learn and improve from one another. He said that as everyone goes forward the goal should be to meticulously document activities and publish articles in journals.

INDIAN TRANSPLANT NEWSLETTER

Speaker – Dr. Sumana Navin

Dr. Sumana Navin began by saying that the genesis of the Indian Transplant Newsletter (ITN) was in the year 1998 as a quarterly publication, and started off with just four pages. It was now into its 52nd issue (November 2017 – February 2018). The newsletter showcases various topics in the field of organ donation and transplantation such as international and national news, experiences of transplant recipients, patient support groups,, case studies and scientific articles. The newsletter also features stories of deceased donors and how they saved lives as well as experiences and interviews of health care professionals in the field. It featured the story of Loretta Andrews, 67, from USA who became the first foreign national to be a deceased donor in India in October 1998 (Vol 1; Issue 3, 1999). It carries information on landmark conferences and meetings, and data on deceased organ donation and transplantation in India. She pointed out that these features were of immense value in tracing the history of deceased donation in India and were very relevant in future discourses.

A series on Difficult Donations was started in the 50th Issue of the ITN with transplant coordinators sharing how they faced challenging situations with regard to the donation process. She encouraged all the transplant coordinators to contribute to the ITN.

Dr. Sumana also said that all the issues of the ITN were now available online (www.itnnews.co.in) with information on the citation for each article.

Rapporteur – Ms. Ann Alex

WHAT IS NEW IN EACH CENTRE - NAGPUR ACTIVITIES

Speaker – Dr. Ravi Wankhede

The centre is interested in seeking accreditation for the Transplant Coordinators' Training Programme as a certificate course on organ donation and transplantation. The Department of Continuing and Adult Education & Extension – The University Grants Commission has described the role of universities as “the preservation, transmission and extension of knowledge and the stimulation of intellectual life and cultural development of the society”. Dr. Wankhede said that the subject of organ donation fits into this definition and with this in mind the Public Relations Officer, Dr. Shyam Madhav Dhond, Rashtrasant Tukadoji Maharaj Nagpur University was approached with the proposal for a certificate programme in Nagpur. However, the exact requirements for this would need to be examined and the feasibility explored.

The Zonal Transplant Coordination Centre (ZTCC) – Nagpur has a new website for the public to access information about the deceased donation programme in Nagpur. The aim of this website is to enable people in search of answers about the programme to find it on the website. It contains information about ZTCC Nagpur and organ donation and transplantation (www.ztccnagpur.org).

Dr. Wankhede then spoke about the constitution of ZTCC Nagpur including the involvement of non-governmental organisations. ZTCC Nagpur took up this opportunity to work with MOHAN Foundation to promote the cause. He emphasised the importance of reporting and the difficulty in maintaining reports.

Q – Can this certificate course be available all over Maharashtra?

A – Yes definitely, we will be first working on making it available Nagpur, then for the rest of Maharashtra.

Q – Can the MOHAN Foundation helpline number be put on ZTCC Nagpur website's homepage?

A – Yes, the number can be put on the homepage.

Q – Any particular reason why the city's waitlist is not displayed on the website?

A – We have thought about it, but the issue is on who will have access to the waitlist. There should be a separate body that is coordinating the waitlist.

Suggestion –

Putting up the stories of the donors along with their pictures on the website would encourage the public.

Rapporteur – Ms. Ann Alex

USE OF SOCIAL MEDIA

Speaker – Mr. Gowtham

Mr. Gowtham began by putting forth the question “What are your insights about social media?” He went on to say that this is the most important question which is asked by any marketing person. Any brand that addresses this query does well in promoting their company’s page. For example, McDonald’s does not make the best burgers in the world but it is very famous because of its marketing strategies. Social media is, us as individuals relating to something bigger than ourselves. It is a message we are trying to bring out from start to end. When an idea is sold it should be sold to the minds of the people for it to be actualised.

He put forth the question ‘how does social media work and does social media have a wide reach?’ With the help of a survey he helped the audience understand this question. The following questions were asked –

- How many have a smart phone? - The majority of the audience had a smart phone.
- How many have a landline number which is used only for broadband connection and not for calling? – The majority used it only for broadband connection.

The same questions asked about 10 years ago would have an opposite response. This shows the progress over the years. In the early years newspaper market was a bit hit, then it moved to the television market and currently the market is in social media. The mindset of the audience is the same, the product is the same, only the medium has changed over the years. Social media is interactive and not boring whereas when it comes to television the audience is only consuming information, there is no interaction involved.

He went on to talk about how marketing is divided into three categories

1. Brand awareness
2. Brand education
3. Brand engagement

Once a relationship is built with the social media audience, the only job left is to engage the audience. As a team trying to market the cause of organ donation it is important to focus on what we are projecting to the viewers. He stressed the importance of tagging, commenting and sharing posts. This would enable posts to have a wider reach. Just one like, share or comment reaches out to a huge audience. The bottom line is to not underestimate the power of a like, share or comment.

Q – How can we reach out more and increase the number of likes on our facebook page?

A –When there is a post on the Facebook page, it is important for everyone to tag, like, share or comment. This would enable the post to reach out to a wider audience.

Q – What is MOHAN Foundation’s Facebook username?

A – @MOHANFoundationIndia

Q – Is there any way to know who is presently on the page?

A – No, we cannot get that information.

Q – How can we engage our 80k followers who have liked our page?

A – We can reach out to the followers or do activities for them.

Rapporteur – Ms. Ann Alex

LET US REFOCUS – Feedback From The Team

Speaker – Mrs. Lalitha Raghuram

Mrs. Lalitha Raghuram began by displaying pictures from the 2013 Advanced Transplant Coordinators’ Workshop. In 2014 we had 196 donors in the country. In 2020 the goal is to increase the number of donors to 1200. She used Mr. Ayush Kejriwal as an example. The reason he stands out among other designers is because in a world filled with light-skinned models he uses dark-skinned models. People are always looking at change, we need to analyse “How is what I am presently doing different from what I did last year.”

A SWOT Analysis was done with the Foundation team to understand the strength and weaknesses. The points were analysed and discussed. The strengths are that the Foundation provides plenty of opportunities, everyone working is passionate for the cause, freedom is given to the employees, the seniors are very approachable, it is an appreciative environment, everyone respects each other, safe work environment for women, team work, provides a future for employees, proud to be associated with it. The weaknesses are there is no proper role clarity, lack of communication, lack of respect for emotional feelings, requirement for a HR employee and administrator, no proper time management, the Foundation is only fire fighting. Points on how we can correct ourselves were discussed. How can the Foundation improve - by spreading the message of organ donation in rural areas, proper delegation of work, should reach out to more states, conduct more public awareness programmes, develop new and innovative types of programmes, and have a recreation day for the employees. Five years down the line where do you see the Foundation - having more international collaborations, accreditation for the E-learning course,, focusing more on publications, an office in each state, fall within the top three NGOs in India. For some, working with the Foundation was not a career, but a mission, a calling.

Rapporteur – Ms. Ann Alex

CONTENT WRITING & INFOGRAPHICS

Speaker 1 - Ms. Thilaka Ravi

Speaker 2 - Ms. Amala

Ms. Thilaka Ravi began by saying all editors could relate to the statement ‘an editor’s life is miserable’. A lot of errors can be avoided if writers revisit their previous tracked changed documents and check the mistakes they have previously made. An example of a common mistake which writers make is ‘She will come between 10 am to 12 pm’, the correct sentence would be ‘She will come between 10 am and 12 pm’. When writing an article you want the world to read, you cannot just be a good writer you need to be a smart writer for search engines to recognise you. She briefed the audience with tips on how to target an audience. It is important that a writer improves his writing skills, this would enable information to be easily accessible to the readers. If an article has a lot of information which is difficult to understand, all the difficult information should be on one page and the next page should have all the information explained. When writers have catchy titles, they can trick Google into putting the article under a lot of different topics. One must always remember that Google loves questions. When you write an article it is better to have hyperlinks this would enable readers to not leave the page. When quoting famous authors one must not quote them at the beginning or end of their article but in the middle, as your article would get lost in the list of articles under that particular author’s name. Writers should avoid spelling errors, cliché sentences, not have a lot of text in bold except for the keywords.

Ms. Amala illustrated the meaning of infographics with the help of examples.

Rapporteur – Ms. Ann Alex

MY JOURNEY AS A MARATHONER

Speaker – Ms. Jayanthi Sampathkumar

Ms. Jayanthi Sampathkumar began by speaking about what motivated her to start running, especially running in a nine-yard saree. She saw someone in the Guinness Book of World Records running in a suit and thought to herself if she could run in a saree. After looking it up she found that there was an option in the Book to run in a saree under five hours. Initially people would get confused whether she was part of the audience or one of the contestants. She received constant family support which helped her to push herself. When she reached around 39.3 kms she was ready to give up, but she said that she knew she was in control of the next few steps and what decision she made would define her outcome. She encouraged everyone to just take the next step in life and to push yourself to work harder to achieve your own target. It doesn’t matter how you start, it’s how you finish that matters. When you push yourself to do something in life there will always be resistance.

Q – Everyone has a point in their life when they are faced with a huge wall in front of them, how does one overcome the physical inhibitions?

A – Think to yourself, what is the worst thing that could happen. It is okay to stop and take a break and analyse.

Q – How many sarees do you have?

A – Around 100 to 150 from almost every state of India!

Q – We all work in a very busy and stressful environment, how do you make time for yourself? Is running your stress buster?

A – It is very important how you plan your day. You need to make time for yourself. If you don't love your life you will automatically not be interested about what you do in life.

Q – After you started running how have you changed as a person? Have you changed mentally or physically?

A – Both have changed in my life, your physical strength helps your mental strength. My mental strength is what's helping me at work right now. My mental strength helps me through my day. I've also got feedback from the people around me that I've become a calm person.

Rapporteur – Ms. Ann Alex

DONATION AFTER CIRCULATORY DEATH

Speaker - Dr. Darius Mirza, UK

Dr. Darius Mirza began by explaining Donation after Cardiac Death (DCD) which is also known as Non Heart Beating Donation (NHBD). He focused on leveraging organ donors from circulatory death. He pointed out that 10 European countries agreed with the death criteria, it also included the definition of NHBD. The Maastricht criteria was explained in detail. The UK has seen growth in the number of donations over the past few years. The types of NHBD such as controlled and uncontrolled were explained. When counselling families, it is easier to approach a family whose loved one has died of cardiac arrest than a family whose loved one is brain dead. Grieving families find it difficult to comprehend the concept of brain stem death (BSD). He touched on the flow chart confirming circulatory death, the process of organ retrieval, donor assessment, practical considerations and donor warm ischemia. It was also emphasised during this session is that NHBD should not be considered as Plan B to improve organ donation, as BSD is always the perfect approach for organ donation.. A new innovative idea of preserving the organ such as liver was put forward to the audience. The machine is called OrganOx Metra. It perfuses the liver which will make the liver viable after retrieving till the time of transplant. The OrganOx Metra costs over 10 million rupees. He then ended with the question 'DCD donation in

India – Are we ready?’ In India the withdrawal of treatment is not practised. A key factor is that there should be trust between the patient and doctor.

Rapporteurs – Mr. Britzer Paul and Ms. Ann Alex

EXPERIENCES AND KNOWLEDGE SHARING FROM GIFT OF LIFE INSTITUTE, USA

Speaker – Dr. Sumana Navin and Ms. Sujatha Suriyamoorthi

Dr. Sumana Navin and Ms. Sujatha Suriyamoorthi shared their experience of the Mini Fellowship in Organ Donation at the Gift of Life Institute (GOLI), Philadelphia, USA. It was a two-week fellowship funded by MOHAN USA that covered the best practices of Gift of Life Donor Program, observational learning, skill-based training special event, and a workshop. The National Organ Transplant Act of 1984 allows transplantation to be legal in USA. The Gift of Life Donor Program is the most successful organ procurement organisation (OPO) in USA. OPOs are independent non-profit organisations which are separate from transplant centres. They have agreements with hospitals to coordinate the donation process. the Gift of Life Donor Program covers parts of three states and had 540 deceased donors in 2016 with an organ donation rate of 49 per million population (pmp). According to the United Network for Organ Sharing the ODR for USA in 2016 was 30.98 pmp.

Dr. Sumana highlighted that Mr. Howard Nathan, President & CEO, Gift of Life Donor Program has been a part of the organisation for the past 40 years. She pointed out that they had observed that during a retrieval process the transplant coordinator is the one who leads the show. In fact, before the organ retrieval begins, the transplant coordinator reads from a ‘Moment of Honor’ card and requests everyone to take a moment in silence to honour the deceased donor. The Family Support Service respects donors by having a donor recognition kit which contains an appreciation certificate, a medal, a pin, a book and a wristband with a message “Be an Organ Donor” which is given immediately after the donation if the family wishes to display the kit during the funeral service. Around a month after the donation they make a call and inform the donor’s family about the condition of the recipients without sharing the identity of the recipients. They also facilitate communication between the donor family and the recipients. Dr. Sumana and Sujatha also had the privilege of attending a celebration programme to honour the organ, tissue and cornea donors and their families called ‘Life and Legacy’. Also displayed during the programme was a quilt called ‘Threads of Love Donor quilt’.

Rapporteurs – Ms. Ann Alex and Mr. Britzer Paul

ORGAN SHARING REGISTRY

Speaker – Ms. Suganya Ramar

Ms. Suganya Ramar began with the aim and functions of an online transplant registry to help organ failure patients to receive a transplant and live a normal life. MOHAN Foundation maintains the registries for three states - Tamil Nadu Network for Organ Sharing (TNOS), Kerala Network for Organ Sharing (KNOS) and the Rajasthan Network for Organ Sharing (RNOS). She focused on explaining the TNOS registry such as the information availability, registries, waitlist details, and deceased donor details. This information is not available to the public, but only to authorised persons. The process to upload information by the various hospitals in Tamil Nadu was also explained.

Discussion: This information was useful to the other MOHAN Foundation state office heads with regard to documentation and implementing a successful organ donation and transplantation programme.

Rapporteurs – Mr. Britzer Paul and Ms. Ann Alex

E- LEARNING MODULE – TRANSPLANT COORDINATORS' TRAINING

Speaker – Ms. Ann Alex

Ms. Ann Alex spoke about MOHAN Foundation's unique training programme for transplant coordinators. Among the various training programmes conducted by the Foundation, the e-learning programme is a one-year programme ideal for working professionals in the field of transplant coordination. Presently there are 68 modules and 48 video lectures by renowned international and national faculty. As it is an online programme it enables a student to learn at his or her own pace from their place of convenience. Through the Learning Management System MOODLE the resources are put forth through various methods such as video lectures, PowerPoint Presentations, and text. Activities such as Quizzes, Assignments, Forums, Chat, and Choice keep the students engaged. The Big Blue Button (BBB) enables the faculty and students to have a video conference class room setting. Other features such as the HTML Block helps students gain more about information about organ donation and transplantation around the world. The E-learning course will expand the reach of the transplant coordinators' training programme.

Q – Is the course accredited by any university/institution?

A – As of now no, but there are discussions going on.

Q – Who can join?

A – Anyone who is interested including MOHAN Foundation employees.

Rapporteurs – Mr. Britzer Paul and Ms. Ann Alex

PHOTOGRAPHY- HOW TO TAKE A GOOD PICTURE/ VIDEO & WHEN

Speaker –Mr. T.S.Siva Shankar

Mr. Siva Shankar focused on helping the participants understand the difference between a good and poor quality picture/video. The importance of a good photo and video were highlighted. When clicking a picture there should be a frame to the picture. One should be clear on whether they want the subject or the background in the picture to be the focus. Location of the picture/video plays a huge role in the quality of the picture/video, for example when taking a photo outdoors in the afternoon there will be a lot of shadow from the sun and the picture/video will not come out very well. The subject should face the light not be behind the light. This session made it clear on how a photograph should be taken in the view point of lighting, frame, focus, colour and area, with examples from photos taken from the MOHAN Foundation webpage. Comparisons were made between a good photo and a bad photo. This comparison was made in order to correct the mistakes committed earlier and to be conscious that it is not repeated.

Discussion: Dr. Sunil Shroff suggested that everyone should make it a point to take good photographs as images capture the audience. He also suggested that participants take up an online course on photography.

Rapporteurs – Ms. Ann Alex and Mr. Britzer Paul

HOW TO WRITE A GOOD PRESS RELEASE?

Speaker – Ms. Pallavi Kumar

Ms. Pallavi Kumar stressed on how to make events newsworthy, what warrants a press release, the experience of the Qutab Minar press release. Questions one should ask when writing a press release are - is there any value in this story, would I read this story. The news that is given should be interesting. If journalists do not consider the event newsworthy it will not get much coverage. Never start with long introductions, it is always better to first go straight to the point and be precise. It must be written in the third person. An outline was given on how the sections of a press release should be framed, namely: time, title, format, facts, precise writing, boilerplate and images. Editors should let any grammatical or typographical errors creep in. She had also conveyed the importance of networking with the press / media. She also shared her experience on the Qutub Minar being lit green during the event SAMARTHAN 2018 and how she had written that press release.

Discussion: Dr. Sunil Shroff suggested that all offices build a good rapport with the media. Problems that were faced during the press release for SAMARTHAN 2018 were also discussed taking into account the Qutub Minar press release.

Rapporteurs – Mr. Britzer Paul and Ms. Ann Alex

WHAT IS NEW IN EACH CENTRE - JAIPUR ACTIVITIES

Speaker – Mr. Prajesh Taneja

Mr. Prajesh Taneja spoke on the activities undertaken by the MFJCF – Navjeevan team such as the Gram Panchayat Project, Donor Memorial Calendar, Road Name after a Deceased Donor, Sahodya Project, MoU with Dainik Bhaskar, Transplant Institute at Jaipur. The people of Jaipur did not have as much awareness about organ donation as they did for blood and eye donation. The team wanted to reach out to the villages of Jaipur to spread the message of organ donation by giving awareness presentations to the local people, school teachers and students of each Gram Panchayat. He listed out all the Panchayat Samitis covered so far and spoke about their future plan to cover more Panchayat Samitis. The Donor Memorial Calendar was created to honor organ donors. The calendar contains 10 paintings that were selected from students of 20 schools for the calendar. In a one of its kind initiative a road in Kanwar Nagar Panchayat was named after deceased donor Mr. Dikshant Thadani.

Rapporteur – Ms. Ann Alex

MOHAN FOUNDATION'S MEMORANDUM OF UNDERSTANDING WITH NHS BLOOD AND TRANSPLANT, UK

Speaker – Dr. Sunil Shroff

Dr. Sunil Shroff enlightened the audience about the Memorandum of Understanding (MoU) that MOHAN Foundation signed with the NHS Blood and Transplant (NHSBT), UK in January 2015. Ever since the MoU was signed, both the NHSBT and MOHAN Foundation have worked together to share experience and gain knowledge of each other's practices and expertise. Collaborative working and sharing practices will continue to progress and support India and UK in improving donation rates, and working towards saving and improving lives.

Rapporteur – Dr. Sumana Navin

ORGAN DONATION HELPLINE APP AND REPORT

Speaker – Dr. Hemal Kanvinde

Dr. Hemal Kanvinde briefed the audience on MOHAN Foundation's Toll Free Organ Donation Helpline (1800 103 7100), its counsellors and the impact. She listed out the various languages available through the helpline and the number of calls received in each language. In 2017 a total of 11269 calls were received with the maximum received in Hindi & Marathi. Queries such as general information on organ donation, patient query and trading of organs were raised. An analysis of counsellors' answers to calls is done to ensure that there is improvement. Impact of the helpline was visible where a call was received on 19th September 2017 as a family wanted to donate the organs of their 11-year-old child Tejashree Shelke who was declared brain dead. On

6th November 2017 the helpline received a call from Mr. Vaibhav Sharma whose brother met with an accident and died, his brother's corneas were donated. On 2nd November 2017 the helpline received a call from Mr. Gopinath whose grandfather had passed away two hours before. The family donated his eyes. She spoke about various platforms where the helpline could be publicised and ended with the Organ Donation App where counsellors can access and share information regarding eye banks, skin banks, body donation information, organ transplant hospitals etc.

Rapporteur – Ms. Ann Alex

MEMORANDUM OF UNDERSTANDING – MOHAN FOUNDATION WITH NHS BLOOD AND TRANSPLANT, UK

Speaker - Dr. Satya Vrat Sharma

Dr. Satya Vrat Sharma addressed the gathering via Skype. He mentioned that after signing the MoU, several activities have been carried out.

MoU Achievements

1. Members from each organisation meet annually to discuss ideas and plan activities which are aimed at helping to improve organ donation rates among Black, Asian and Minority Ethnic (BAME) communities in the UK and also improving donation rates in India.
2. He (Dr. Satya Vrat Sharma) has been working closely with the Bishop of Litchfield and the „Flesh & Blood“ initiative working to raise awareness of donation amongst the BAME communities. This initiative is supported by the Archbishop of Canterbury.
3. Darius Mirza, Consultant, Hepatobiliary and Transplant Surgeon, University of Birmingham, UK is currently on a secondment in India where he is sharing his knowledge and expertise with surgeons in India.
4. National Organ Retrieval Courses in India - Integrated Liver Care Foundation, in partnership with the Indian Society of Organ Transplantation (ISOT) and the MOHAN Foundation with experts from Oxford and Birmingham Universities
5. Donor Optimisation App – Developed by Dr. Sridhar Nagaiyan, Former NHSBT Regional Lead for Organ Donation, Midlands, UK and presently Senior ICU consultant in Kauvery Hospital, Chennai, India in partnership with MOHAN Foundation. The App was shared among the health care professionals in the UK and India through CLOD and SNOD communities at the Level Meetings (hospitals with similar Organ Donation potential share best practice), ICU trainees Organ Donation SIM course, CLOD induction courses

6. Dr. Sumana Navin, Course Director, MOHAN Foundation attended Deceased Donation Course for Intensive Care Medicine (ICM) trainees in Nottingham and visited NHSBT Tissue Services, Liverpool, UK
7. Faculty from UK invited to conferences, transplant coordinators' workshops, tissue banking workshops, and National Deceased Donation Clinical Simulation Workshop in India

Dr. Sharma stressed on working more intensively with the BAME communities and sought MOHAN Foundation's expertise in getting celebrities like cricketers and actors to support organ donation and garner attention from the BAME communities in the UK.

Rapporteur – Dr. Sumana Navin

DAY 2 – 24th MARCH 2018

INNOVATIVE ACTIVITIES IN ADVOCACY PROGRAMME & INTERNSHIP PROGRAMME

Speaker – Dr. Hemal Kanvinde

Dr. Hemal Kanvinde took a session on the tools used to engage the public during an organ donation awareness programme.

- Role Play and Protocol for deceased organ donation using placards
- Memory Game
- Flipchart

Mr. Ruban Victor moderated activities on early identification of the patient, role of grief counsellor and the organ donation process. The benefit of the role play with placards is that it will have a visual impact in the minds of the participants. Mr. Raja explained the concepts of organ donation using a flipchart (in Tamil) which was developed to address a small group.

Dr. Hemal Kanvinde mentioned about utilising the interns in MOHAN Foundation. She presented the work carried out by the interns in organ donation awareness, framework for programming the database, and engaging them in the Foundation's activities. Interns usually hail from the social work background, overseas students also intern at the Foundation.

Discussion - Ms. Pallavi Kumar mentioned that flipchart can be used for smaller group for about 10 to 15 minutes using more of a pictorial representation.

Rapporteurs – Ms. Sunitha Velankanni and Ms. Mareena Thomas

INNOVATIVE ACTIVITIES IN TRAINING PROGRAMMES FOR TRANSPLANT COORDINATORS AND ICU WORKSHOPS

Speakers - Dr. Sridhar Nagaiyan and Dr. Sumana Navin

Dr. Sridhar and Dr. Sumana spoke about the innovative activities done during training programmes for transplant coordinators and ICU workshops to enhance the learning experience. Some of these included the use of mobile apps, simulation, quizzes, group activities, communication exercises, organ retrieval and packing exercise, role play, and dramatic use of film/TV clips. A quiz titled 'Dead or Not Dead' on the diagnosis of brain-stem death which was created by Dr. Dale Gardiner, UK and Dr. Sridhar was immensely popular. The Donor Optimisation app serves as a quick reference guide and is very useful for all ICU staff. Dr. Sridhar also spoke about the use of simulation using an iPad/laminated sheets for participants to address the changing clinical state of a brain-stem dead patient (optimization). Each training

activity was explained to help the audience understand the rationale and impact on learning. Dr. Sumana ended the session with a sample presentation on public advocacy with impactful data from ‘The Conversation Project’ that transplant coordinators could use. She emphasised that when one used data, the source should always be mentioned (www.conversationproject.org).

Rapporteur – Dr. Sumana Navin

WHAT IS NEW IN EACH CENTRE – TAMIL NADU ACTIVITIES

Speaker – Ms. Sujatha Suriyamoorthi, Ms. Sunitha Velankanni, Mr. Venkatesh, Mr. Ragavan, Mr. Raja, Ms. Persis, Mr. Nishanth and Mr. Santhosh Kumar

The session started with an introduction by Ms. Sujatha Suriyamoorthi. She briefed the audience on the Memorandum of Understanding (MoU) signed between MOHAN Foundation and TRANSTAN (Transplant Authority of Tamil Nadu) under which MOHAN Foundation’s trained transplant coordinators were placed in various government hospitals in Tamil Nadu. Following that the transplant coordinators spoke on the various activities carried out by different government hospitals across the state between January 2017 and December 2017.

Mr. Santhosh Kumar G, Government Stanley Medical College and Hospital (GSMCH), Chennai- In 2017, there were 18 brain deaths certified in the hospital out of which 16 families were approached for organ donation (2 families left the hospital against medical advice). Among the 16 families, 13 families consented for organ donation. As a result 73 organs and tissues were retrieved from 11 donors (2 potential donors had cardiac arrest, hence organ donation could not take place). 2017 was another landmark year in the transplant history of Tamil Nadu as the State’s first double hand transplant was performed at the Government Stanley Hospital. Mr. Santhosh Kumar addressed the challenges faced while counselling and coordinating the donation process as that was the first of its kind.

Ms. Sunitha, Mr. S. Ragavan, Mr. P. Periyannayagam (Rajiv Gandhi Government General Hospital, Chennai). The deceased organ donation in RGGGH was briefed by Mr. Ragavan. 74 brain deaths were identified from January 2017 to December 2017. However only 20 brain deaths were certified and the remaining patients had cardiac arrest before even conducting the brain stem death testing. All the 20 families whose loved one was certified brain dead were approached and 16 of them agreed for organ donation. However the organs and tissues were retrieved only from 12 donors (86 organs and tissues) as the remaining 4 brain dead patients had cardiac arrest. The challenges and issues faced during coordinating the donation process was discussed by the team. Some of them were not having Standard Operating Procedures (SOP) in the hospital; hierarchical issues in reporting; extended working hours.

Mr. S. Venkatesh, Madurai Medical College and Government Rajaji Hospital (MMCGRH), Madurai. The deceased donation programme in MMCGRH was established in 2017. There were 5 brain deaths certified in the hospital and all 5 families agreed to donate their loved ones' organs. Organ retrieval was facilitated from 4 donors which resulted in retrieval of 22 organs and tissues (one potential donor had cardiac arrest). The MMCGRH performed the first heart transplant in November 2017. MMCGRH was the first government hospital in tier 2 city to perform a lifesaving heart transplant.

Mr. N. Raja, Government Kilpauk Medical College and Hospital (GKMCH), Chennai. The first tissue bank in the state of Tamil Nadu was established at the GKMCH. In 2017, 3 skin grafts were retrieved by the GKMCH and the donations were from Rajiv Gandhi Government General Hospital. Mr. Raja discussed the challenges faced in establishing the deceased donation programme – lack of specialists, manpower and infrastructure; lack of management support.

The partnership with Government Mohan Kumaramangalam Medical College Hospital (GMKMCH), Salem and Coimbatore Medical College and Hospital was established only in February 2018. Efforts have been taken to initiate the deceased donation programme in both the hospitals. The transplant coordinators were involved in hospital licensing procedure, in-house sensitisation programmes for medical and para-medical staff, counselling for tissue donations after circulatory death (skin, cornea) and public awareness.

Rapporteur – Ms. Sujatha Suriyamoorthi

WHAT IS NEW IN EACH CENTRE – CHANDIGARH ACTIVITIES

Speaker – Mr. Sudhir Dewan (via Skype)

Mr. Sudhir Dewan, Director, spoke about how they had conducted a total of 123 programmes addressing 1600 over 12 months with an average of 10 programmes per month. A new MoU has been signed with a Rotary Club and the MOHAN Foundation Chandigarh office. He said that they had also reached out to the Chief Minister of Chandigarh and planned to sign a MoU with the Government of Haryana. Promotional activity through a dance performance was done in Delhi Public School, also collaborated with the Vidhan Sabha at Punjab to conduct awareness programmes for 10 sessions with 60 participants each.

Rapporteurs – Ms. Mareena Thomas and Mr. Britzer Paul

WHAT IS NEW IN EACH CENTRE – MUMBAI ACTIVITIES

Speaker – Mrs. Jaya Jairam and Mr. Amit Shenoy

Mrs. Jaya Jairam shared about their recent successful story behind the “Life before Ashes” event and the various places it was exhibited. A video on the concept behind “Life before Ashes” was screened. Videos clips on recipients, donor family members and other medical professionals on improving organ donation were also screened. They participated in a fund raiser marathon to support the cause of organ donation. Transplant Recipients Indian Organisation Meant to Provide Hope (TRIOMPH) is a community which acts as a voice for Indian transplant patients with an aim to discuss transplant related problems and documents, provide medicines, laboratory tests and annual medical screening for specific tests at subsidised costs.

Rapporteur – Mr. Britzer Paul

WHAT IS NEW IN EACH CENTRE – TELANGANA ACTIVITIES

Speaker – Dr. Bhanu Chandra

Dr. Bhanu Chandra spoke about a skit done for the public in spreading awareness on organ donation. At present all awareness programmes are conducted in collaboration with Jeevandan, Telangana. Difficulties with the neurologists in a hospital stopped transplants from taking place. The success story behind auto transplant was shared.

Rapporteur – Mr. Britzer Paul

WHAT IS NEW IN EACH CENTRE – DELHI ACTIVITIES

Speaker – Mrs. Pallavi Kumar

Ms. Pallavi Kumar began by speaking about the unique event during which the Qutab Minar was lit up in green for organ donation during Samarthan 2018. The event also featured a standup comedian who entertained the audience; this was in aid of organ donation. She spoke about how she raised funds for organ donation by running the Airtel Delhi Half Marathon; the Foundation also won the Second Runner-Up of 'CSO WITH MOST SUPPORTERS' challenge collecting an amount of Rs.3,38,525/- through 70 supporters. As the prize money, the Letz Dream Foundation gave an award of Rs. 54,738/- The total funds raised during the ADHM Raise-A-Thon 2017 was Rs.3,93,263/-. T-shirts with new designs promoting organ donation were made to raise funds. A counselling film was developed in Hindi (adapted from a film by NHS Blood and Transplant, UK) to understand the concept of a good and poor approach for organ donation.

Rapporteur – Ms. Ann Alex

MOHAN USA

Speaker - Dr. Anirban Bose

Dr. Anirban Bose, President, MOHAN USA spoke about the contributions of MOHAN USA thus far. MOHAN USA, Inc. is a 501(c) (3) registered nonprofit organization that was formed to increase awareness about organ shortage and promote transparency and ethical organ transplantation in India and the rest of the world. He then went on to speak about the upcoming fundraiser in June 2018 in Seattle, USA.

Rapporteur – Dr. Sumana Navin

MULTI- CITY STUDY OF BRAIN-STEM DEATH AND COUNSELLING FOR ORGAN DONATION IN GOVERNMENT HOSPITALS

Speaker - Dr. Sumana Navin

Dr. Sumana Navin handed out a questionnaire to all the participants which was followed by a discussion on the importance of collecting data and auditing brain-stem death and counselling for organ donation in the government hospitals in various cities. This would be a key step in involving all the stakeholders and improving the deceased organ donation programme in the hospitals.

SURVEY - MULTI CITY GOVERNMENT HOSPITALS BRAIN STEM DEATH AND DECEASED ORGAN DONATION

Name of the Hospital:

Name of the contact person:

Contact Details:

About the Hospital		
Department of Transplant Services		
Details of transplants in the hospital (live or deceased) – Registration details and the organs being transplanted		
Full time consultants		

Full time surgeons who do transplants	
Trauma Unit	<input type="radio"/> Yes <input type="radio"/> No
If yes no. of beds	
Case load per day	
Neurosurgery	<input type="radio"/> Yes <input type="radio"/> No
Case load of no of surgeries per month	
ICU	
No of ICUs	
Is there a separate ICU for trauma	<input type="radio"/> Yes <input type="radio"/> No
Is there a separate ICU for neurosurgery	<input type="radio"/> Yes <input type="radio"/> No
Do you get head injury and brain deaths	<input type="radio"/> Yes <input type="radio"/> No
Average no. of trauma and ICB cases every month	

BRAIN STEM DEATH AND DECEASED ORGAN DONATION DATA: MONTH-WISE DATA

No. of brain stem deaths certified (first brain stem death certification) -

No. of families approached for organ donation after first brain stem death certification -

No. of families that consented for organ donation -

No. of families that did not consent for organ donation -

Reasons for refusal

- Prolonged process/time factor
- Grief
- Not happy with treatment provided in hospital
- Next of kin not available
- Extended family members did not agree
- Religious reasons
- Wanted financial compensation
- Wanted to know about/meet recipients
- Wanted educational support for children
- Any other reason, please specify -

No. of cases where family consented but deceased donation did not happen -

- Medicolegal issues
- Cardiac arrest
- Contraindications/medically unsuitable

- Any other reason, please specify -
- Total number of deceased donations in the month –

Rapporteur – Dr. Sumana Navin

WHY IS IT IMPORTANT TO DO “DAILY REPORTING” - AWARD & PENALTIES

Speaker - Mrs. Lalitha Raghuram

Mrs. Lalitha Raghuram stressed the importance of documenting one’s work-related activities in the Daily Reporting interface. This would not only be an official record of the work done by the individual, but it would also benefit each one to develop the skill of documentation.

WAY FORWARD

Speaker – Dr. Sunil Shroff

Dr. Sunil Shroff began with the quote “Service to society is the rent we pay for living on this planet” – Dr. Joseph Murray

He emphasised that awareness, capacity building, counselling and influencing policy and legislation is the role of the Foundation. The statistics of Kidney, Liver, Heart and Lung transplants and the rising trend in deceased organ donation in India was projected. States like Tamil Nadu, Maharashtra and Telangana performed well in 2016 with 180, 132, and 106 deceased donors respectively. In Tamil Nadu, live kidney transplants are plateauing whereas deceased donor kidney transplants are going up. Promoting the family donor card would encourage more families to pledge.

The Foundation’s core training programmes are for transplant coordinators, organ retrieval for surgeons (with the Oxford group, UK), ICU staff, nurses, and the police. The focus needs to be on keeping track of the impact of the trained transplant coordinators. Documentation is very important to showcase the work that is being done. . We should create visibility about our work by publishing in journals, creating microsites, and using infographics. We should also ensure quality in the donation process through establishing a system involving Donor Detection, Donor Declaration, Donor Viability, Donor Maintenance, Family Interview, Recovery, Distribution, and Transplant.

Quality Assurance (QA) and Performance Improvement (PI) programmes for transplant centres using objective measures are important for the future. Some examples of objective measures are patient survival at one year, graft survival at one year, rejection episodes, readmissions within 30 days post transplant, cold ischaemia time, number of declined organs, mortality on the waitlist. He also spoke about working on the costing of a kidney, liver and heart transplant in a private middle level corporate facility for transparency. He ended by saying that the Indian transplant programme would be largest in the world in 10 years’ time.

Rapporteurs – Dr. Sumana Navin and Ms. Sunitha Velankanni

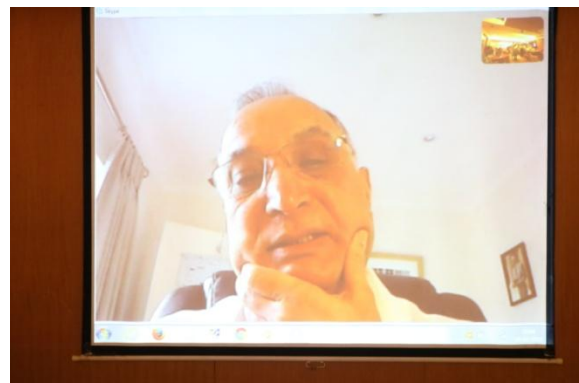








MONTH	PLANNED	ACTUAL
January	12	18
February	8	9
March	8	5
April	8	7
May	8	12
June	8	10
July	8	8
August	10	11
September	8	12
October	8	9
November	8	11
December	8	11
TOTAL	100	121








Become a Life Member & Help Us in Saving Lives

MOHAN Foundation has helped save over 5000 lives through organ and tissue donations. It has helped give momentum to organ donation programme through advocacy, capacity building, conducting workshops and counselling and supporting organ donation families.

All our services are rendered free. We are guided by the Transplantation of Human Organs Act, 1994, where no organ can be bought or sold. Hence, we do not pay anything to the organ donor family or do not receive any monetary benefit from the recipients. We survive purely on the philanthropy of the community.

Recognizing the important work that we have undertaken, we have received support from philanthropically minded individuals, corporate donors, and trusts. We have a 50% tax exemption status under Section 80G and a 100% tax exemption status under Section 35AC of Income Tax Act, 1961. We are approved recipients of foreign contributions under the Foreign Contribution Regulation (FCRA) Act, 1976.

Receive a Life Membership Kit for Organ Donation Advocacy –

-  A Life Membership certificate from MOHAN Foundation office
-  Ten (10) Organ Donor Cards
-  Five (5) brochures of Life Pass It On
-  Two (2) Organ Donation posters
-  CD of 20 slides on Organ Donation with list of 100 FAQ's for public advocacy
-  Regular e-newsletters of our activities
-  Discounts for all our paid fund-raising events
-  A T-Shirt on organ donation
-  Premium Membership to our website where you can access all our material
-  Organ Donation Ribbon
-  Organ Donation Badge

MOHAN Foundation

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Email: mohanfound@gmail.com

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Carry A Donor Card

