



FOURTH COLLABORATIVE CONCLAVE
for Organ Donation

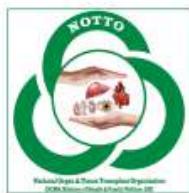


Coming Together to Save Lives



FOURTH COLLABORATIVE CONCLAVE FOR ORGAN DONATION





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FOURTH COLLABORATIVE CONCLAVE for Organ Donation



About Collaborative Conclave

The Collaborative Conclave for Organ Donation is a common platform for all the NGOs working on organ donation in India. It was conceived in 2016 with the vision of streamlining the efforts of the Government and the NGOs to work jointly to promote the cause of organ donation in India. Since 2016, ORGAN India, under the aegis of National Organ & Tissue Transplant Organization (NOTTO), has made sincere efforts to bring all the regional NGOs and other stakeholders working on organ donation on one single platform through an annual 'Collaborative Conclave for Organ Donation'.

ORGAN India firmly believes that a combined force of all organizations across India, working together to spread awareness on organ donation to millions of people in all corners of the country is the best way to move forward. Before the Conclave was initiated, all NGOs in India were working in isolation and were not well acquainted with one another, while some were not on the radar of the government.

The 'Collaborative Conclave for Organ Donation' has become an essential annual event for all the organizations working on organ donation in India. National and regional government and non-government stakeholders come together to discuss and identify issues and challenges, come up with possible solutions, and discuss how to move forward collaboratively in the ecosystem of organ donation. It enables stakeholders to address everyone's concerns under one umbrella, thus strengthening public policy advocacy initiatives.

Collaborative Conclave for organ donation aims at:

- **Network building** - A platform for open dialogue and brainstorming between members of NGOs and Government representatives.
- **Information exchange** - NGOs share their successes, achievements and best-practices with each other and the Government.
- **Identifying, discussing and resolving the challenges** - Facilitating cooperation between all stakeholders to find solutions to challenges faced.
- **Strategizing**: Focusing on the same goals and utilize combined network to reach out to millions of people in all parts of India.



1st



2nd



3rd



4th



FOURTH COLLABORATIVE CONCLAVE for Organ Donation



The Fourth Collaborative Conclave for Organ Donation was held on February 28th, 2020 at Juniper Hall, India Habitat Centre, New Delhi. The Conclave was hosted by ORGAN India, under the aegis of NOTTO, for NGOs and Government Stakeholders from across India. Bringing organizations working for organ donation onto one platform rather than working individually is the goal of the Conclave. It was a resounding success as the participants discussed many innovative ways to spread awareness and collaborate to further the cause of organ donation through effective utilization of various tools for mass outreach.

The day-long conclave was inaugurated by Dr. Vasanthi Ramesh, Director, NOTTO (National Organ and Tissue Transplant Organisation), Ministry of Health and Family Welfare along with Ms. Anika Parashar, Chairperson, Parashar Foundation, Ms. Eeda Gujral Chopra, Trustee, Vijaya Gujral Foundation, Dr. Harsha Jauhari, Technical Advisor, NOTP, DGHS, Dr. Promila Gupta, Principal Consultant, DGHS, MoHFW, GOI, Dr. Anil Kumar, Additional DDG, NOTP Program Officer, MoHFW, GOI and Ms. Sunayana Singh, Co-Founder & CEO, ORGAN India. Dr. Ramesh lit the lamp and set the ball rolling.

Around 55 participants from all across India participated in the conclave. The event was attended by the officials from government organisations such as NOTTO, Ministry of Health and Family Welfare, ZTCC Pune, ROTTO Northern Region, PGI Chandigarh, and Lady Hardinge Medical College. People from various NGOs working on organ donation in states such as Assam, Maharashtra, Rajasthan, Haryana, Madhya Pradesh, Odisha, and Chandigarh also attended.

MOHAN Foundation, Shine India Foundation, Muskan Group, A Million Pledges, Dadhichi Deh Dan Samiti, Zublee Foundation, Rebirth Foundation, MOTHER, NDTN, Maharishi Dadhichi Dehdan Angdan Samiti, Apex Kidney Foundation, The Restoring Force, and The Pravin Agarwal Foundation were some of the NGOs present. Officials from NDTV and The Times of India also attended the event. Donate Life, Light a Life Reena Raju Foundation, Gift Your Organ, Shatayu and Gift Of Life Adventure were some organisations that could not be present but were there in spirit.

This Conclave, we instituted the Kirti Parashar Oration in honour of our former Chairperson, Late Mrs. Kirti Parashar. We were privileged to have the first Oration delivered by Dr. K. R. Balakrishnan, Chairman & Director, Institute of Cardiac Sciences, Director of Heart & Lung Transplantation Programme and Mechanical Circulatory Support. Dr. K. R. Balakrishnan is one of India's most successful heart transplant surgeons and was also Mrs. Parashar's surgeon.

Many thanks to our fantastic Team - Dr. Sourabh Sharma, Dr. Geetika Vashisth, Dr. Devansh Vaish, Kavita Puri Arora, Harjeet Singh, M. Deepak and Mohd. Arbaz for the tremendously successful event.





Welcome Note



Ms. Anika Parashar, Chairperson, Parashar Foundation

The day began with Ms. Anika Parashar extending a warm welcome to the delegates from all over India. She invoked the memory of Late Mrs. Kirti Parashar, Former Chairperson, Parashar Foundation, who was the inspirational force behind the conception of this initiative, and said that Parashar Foundation will continue to take forward her vision to encourage organ donation in India.

Talking about the importance of the conclave she said, "There are many interesting seeds that get planted at the conclave every year. There are many very creative and bold conversations that take place on the topic, and as we go on through the course of the year; the conversations that we have, the agendas that we set and the strengths that we discover about each other help us to actually achieve a lot more in the year. In the group, there are lot of interesting conversations, we share our successes, our challenge areas, and in some way, we have become a community in our own right."





Inaugural Address



Dr. Vasanthi Ramesh, Director, National Organ and Tissue Transplant Organisation, DGHS, MoHFW, GOI

Dr. Vasanthi Ramesh, Director, NOTTO (National Organ and Tissue Transplant Organisation), thanked everyone for the enormous work being done by all the NGOs in the domain of organ donation. She said it felt like being at home amid like-minded people at the conclave. It motivated her and NOTTO further to work persistently to promote the cause of organ donation.

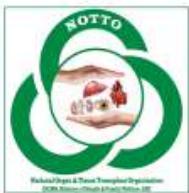
NOTTO has a vision of reaching one million pledges this year on organ donation to celebrate the 25 years of the THOTA Act which came into being in the year 1994. She was confident that they will achieve it.

She was humbled and overwhelmed that a passage on organ donation and green corridor was included in the Class 12th CBSE final English examination paper. Students understood a lot about organ donation after reading it and thus made it possible to reach out to millions of students beautifully in one step. It planted a seed in the young minds.

Dr. Ramesh complimented the efforts of Rajasthan, specifically SMS hospital in Jaipur where the SOTTO has been setup, in coming forward as one of the leaders in organ transplantation. She appreciated Apex Kidney Foundation which has been working tirelessly to promote swap transplantation which was made legal by the Amended Act of 2011. Government is planning approvals for not just the binary swap which is clearly mentioned in the Act, but the domino swaps as well, and is also checking whether it can be inferred from the present Act or needs something more to make it effectual and legal.

She was happy to learn about the ORGAN India's radio program initiative with Gurgaon Ki Awaaz community radio, and other radio programs being aired in Himachal Pradesh and Madhya Pradesh, as it would go a long way in reaching the masses. She stressed that radio has its own outreach and is a wonderful medium to reach the remotest regions. She requested all NGOs to take this forward to use radio to reach out till the last mile. This would be beneficial because the government is now planning to make District Hospitals as NTORCs (Non-Transplant Organ Retrieval Centre), and last mile awareness will help to get consensus at the District and the Primary Health Centre level. She appreciated the work of ORGAN India's graphic designer Ms. Kavita Puri Arora and requested her voluntary support to NOTTO initiatives.





Session 1: Ethics and Law in Organ Donation and Transplantation

Speaker



Dr. Harsha Jauhari, Technical Advisor, NOTP, DGHS, MoHFW, GOI

Dr. Harsha Jauhari was overwhelmed that everyone's efforts are leading to great results in promoting organ donation, and he appreciated the work being done by Dr. Vasanthi Ramesh as the Director, NOTTO, to promote organ donation and transplantation in India. Requested all organisations to adopt the local schools around their area and have regular interaction with those schools, and not just a one-off event.

Ethics and law are in conflict many times. The question is role of ethics in organ transplantation. If one is expecting something from people then there is a need to motivate them as people can't be just expected to donate.

The principle of altruism which is the most important principle in organ donation, doesn't consider the magnitude of the problem with lakhs and lakhs of people dying waiting for an organ.

Incentivisation and help to donor family - Ethics say that incentivisation or points should be there for donors whereas the law says "No". Governments have relief measures for dependents of those dying in accidents such as riots, fire, earthquake etc. but does society have no duty towards the dependents of those who donated organs after death? There is a need to open our minds. What is preventing the system from honouring and incentivising the donor in order to address the acute shortage of organs for transplantation? We are talking about incentivisation not inducement. It could be anything from life insurance policies, lower rates of interest, brownie points for school admissions, jobs etc. It may not have to be cash incentive but they must be done.

Meaning and timing of death in case of brain death or cardio-respiratory death - When do doctors switch off the ventilators? People are willing to withdraw ventilator support, but law doesn't allow though as a doctor main principle should be to save a life. Again, this leads to conflict between ethics and law.

Deceased donation - Can there be Directed Donations in some cases or not? Ethics and law are now conflicting in this scenario. If the body belongs to family then any donation can be made conditional like if someone's family member needs kidney transplant then person should get one. Good ethics don't always make good laws.

Living related transplants - Shrinking families, means no suitable living family member to donate organs. This could lead to emotional blackmail in case of wife giving to husband but ethically it seems correct. So, we don't know how to address these issues.

On unrelated transplants - Law allows only for a near relative to donate and no directed donations are allowed. Even if one has a donor, but the law does not allow the transplant to take place, then the principle that allows people to die due to denial of available treatment cannot be ethically sound. The real crux of the problem is idealism fit for utopia versus pragmatism for 1.3 billion people in a developing country. Try explaining to the patient or to the family members that the reason to deny treatment to them is because of an ethically sound principle.

In conclusion, he said that the application of the principle of altruism to organ transplantation has not gained currency, and yet no civilized society can permit say the purchase of organs. So, what do we do?



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Discussion Points on Ethics

Dr. Avnish Seth, Director, FORT, FMRI Gurugram, brought up a few issues. He said that organ transplants are unaffordable for the common person and is available more for rich people in society, so indirectly in the absence of robust government organ transplantation program, the organs are going from poor to rich. Transportation of organs still pertains to a huge cost and leads to economic issues especially in case of transporting heart from one city to another.

Dr. Jauhari disagreed and said this was true initially almost 2-3 decades ago but now every PM, CM's, PSUs, and most insurance companies provide funds for transplantation. Most government hospitals provide transplants at a hugely reduced rates to economically weaker sections and lower middle class (For example, RML hospital in Delhi has conducted almost 300 transplants totally free including post transplant medicines). Today, the swing has taken place and it is no longer a rich man's treatment. The ethos is changing though whether it is enough or not is a separate issue. We are on the right track but may take time to move ahead.

Dr. Ramesh added that the Government has asked NOTTO to send a status note for guidelines and facilities related to organ transportation, and there is a hope that it will be done soon.





Session 2: NGO Collaboration – Way Forward for All States

Speaker



Arati Gokhale, Central Coordinator, ZTCC Pune

ZTCC Pune is an NGO involved in awareness activities, distribution and allocation of organs and maintaining the waiting list in Maharashtra. It collaborates with NGOs to promote the cause of organ donation.

Ms. Arati Gokhale, said in the two decades she has been in the field of organ donation, the level of awareness has come a long way. Now, families respond very well to the counselling in brain death cases, and this is the result of many local and national NGOs involved in awareness activities, training, CMEs etc. to promote organ donation. Initiatives like rallies, marathons, events etc. have tremendously helped in changing attitudes of people.

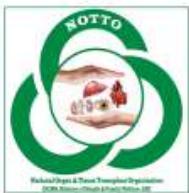
In collaboration with local NGO Rebirth Foundation, ZTCC Pune successfully executed the Guinness World Record in 2018 with the Rotary club of Pune Downtown. For past few years, they have been organizing a short film making competition. Films are shared and used to create awareness on organ donation. Bharat Organ Yatra has been undertaken by a volunteer in collaboration with ZTCC Pune and Rebirth Foundation. For training and academic purposes, ZTCC collaborates with MOHAN foundation and NATCO.

Ms. Gokhale stressed on the fact that collaboration means organisations should work together and share data with each other. They should also share contact numbers of one person in the organisation for any work in their region of function. Strong communication should be maintained. Social media cross branding should be encouraged within NGOs.

Regional NGOs need to work collaboratively in an area as one NGO can't cover everything. For example, ZTCC Pune has reached out to 750 colleges in Pune. It would have been difficult for two people to cover them all, so ZTCC collaborated with Rebirth foundation and designed a training module where volunteers were trained and sent to address awareness sessions. Presentations have been conducted in 722 colleges.

In conclusion, Ms Gokhale emphasized a need for the conclave to work together, learn from each other and replicate successful models in our own region to achieve common goals.

Dr. Vasanthi Ramesh appreciated the efforts put in by ZTCC asked Ms. Arati to contact NOTTO for the Bharat Organ Yatra which is being undertaken by Mr. Pramod Mahajan. She said SOTTOs can be directed to host Mr. Mahajan and support him in his endeavour.



Session 3: Haryana's 'Angdaan Mahadaan' Program

Speaker



Dr. G. L. Singal, Project Coordinator - Beti Bachao Beti Padhao, Secretariat Office, Chief Minister, Haryana

Dr. G. L. Singal began by saying that the organ donation program is in its nascent stage in Haryana. It was launched on 17th January, 2020, in four districts in Haryana as the pilot project. The first meeting was chaired by Dr. Rakesh Gupta, Additional Secretary to Chief Minister, Haryana, and Director, Chief Minister's Good Governance Associates Program, who is the brain behind the program.

Haryana's successful flagship program Beti Bachao Beti Padhao, launched in January 2015 by Hon'ble Prime Minister, led to astounding

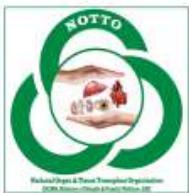
increase in sex ratio in Haryana, currently at 923 females per 1000 males, by implementing drastic, innovative and unique steps. As Haryana lags behind in organ donation, the Honourable Chief Minister decided to apply the same program design and the team to head the Organ Donation and Transplantation Program.

He shared that the collaboration with NGOs is paramount so that the importance of organ donation can be spread at the grassroot level. To begin with, awareness initiatives will be taken up in 4 districts viz. Gurugram, Faridabad, Rohtak and Panchkula under the chairmanship of respective Deputy Commissioners.

Plans are being made to constitute brain death committees in all major hospitals with ICU facilities and the centres identified as trauma centre by Govt. of India have been asked to convert themselves into organ retrieval centres. The first public organ transplant centre in PGIMS Rohtak will start shortly. Targets have been fixed and the audit committee is being constituted to inspect transplant centre compliances.

The awareness sessions have been conducted at few colleges in Panchkula and events have been organized in Gurugram and Rohtak with ORGAN India. The calendar of IEC activities has been prepared and IEC material has been finalized in consultation with ORGAN India.

In conclusion, everyone is putting in their best efforts in the program and Dr. Singal is confident that Haryana will do well in making organ donation a success.



Session 4: Panel Discussion on Promoting Awareness on Organ Donation through Community Radio

Speakers

M.S.H. Beg, Treasurer, Community Radio Association;
Arti Jaiman, Station Director, Gurgaon Ki Awaaz Community Radio, The Restoring Force;
Sharmila Sharma, Station Manager, Gurgaon Ki Awaaz Community Radio;
Sunayana Singh, CEO, ORGAN India

Ms. Sunayana Singh introduced the session and said that ORGAN India had started recording radio shows on organ donation in April, 2019, in an effort to increase mass awareness. Even though no one had done radio before at ORGAN, eventually they figured out that once a few things like a jingle and equipment were organised, it was quite easy to do. They met a few people from Radio and got some good ideas from them.

ORGAN India's radio shows have been broadcasted in Dharamshala, Himachal Pradesh, for almost a year now. Till date, 40 episodes of the show have gone on air which highlights inspirational stories of donor families, transplant recipients, doctors and other stakeholders. The shows are also being aired on two other radio stations viz. Radiomann in Vidisha, Madhya Pradesh, and Gurgaon Ki Awaaz in Gurugram, Haryana.

Radio as a medium of mass awareness is fantastic as it reaches thousands in one shot, rather than awareness sessions at different places which reach out to only a hundred or so people at one time. It is also much cheaper than the other mediums. She suggested that all NGOs should reach out to community radio stations in their states and plan to record and broadcast radio shows on local community radio channels. ORGAN India would be very willing to help everyone get started and share inputs on the same.

Mr. M.S.H. Beg said that community radio is a wonderful medium to create mass awareness as it covers large regions and helps people understand things in their local languages. It reaches out to everyone no matter who they are, whether it's a child or adult, whether someone at home or working in farms, whether rich or poor, whether literate or not, because everyone uses radio. It's an effective medium to make people aware of organ donation as it will help propagate the message, facts and information till the grass root level.

People in remotest areas will get a chance to understand organ and tissue donation and how it will save or improve many lives. Community Radio Association has 265 community radios broadcasting programs across India. He made everyone hear a few jingles on organ donation that he had.

Ms. Arti Jaiman from Gurgaon Ki Awaaz Community Radio shared that her organisation has been working in Gurgaon since 2009 and has been trying to reach out to people through community radio by giving a voice to the unheard. The channel broadcasts for 22 hours every day and though Gurugram is a medical hub of private healthcare, it is not affordable healthcare. Radio as a medium of communication helps reach out to the last mile irrespective of their socio-economic status. Since radio has no face, people ask their queries without any inhibitions and are comfortable sharing their stories. Radio inspires people to come out of their shells and share their problems.

Ms. Sharmila Sharma from Gurgaon Ki Awaaz Community Radio said that it is very important to open-up and speak directly to people in live radio shows. She shared the successes of various campaigns run by the organisation in past and how the same process can be used to create awareness on organ donation.



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Discussion points on radio as awareness medium

Dr. Kulwant Gaur asked whether these radio channels charge for airing shows. Ms. Arti Jaiman replied that broadcasting radio shows require certain financial support to run the radio and the organisation. Thus, community radio stations charge a meagre amount to sustain themselves which is only 4 INR per second. NGOs can set aside this amount as part of their IEC expenditure and support radio stations by paying the minimum charges.





Discussion Rounds - Moderated by Ms. Anika Parashar

Discussion Round 1

NOTTO Donor Card Registration by NGOs, How NGOs can get a Login ID (including demo), Common calendar for awareness events throughout the year where all NGOs can collaborate

Discussion Leaders

Dr. Vasanthi Ramesh, Director, NOTTO;

Dr. Anil Kumar, Addl. DDG, NOTP Program Officer, MoHFW, GOI;

Dr. Promila Gupta, Principal Consultant, DGHS, MoHFW, GOI

Dr. Vasanthi Ramesh requested all NGOs to increase their awareness drives in schools, colleges, communities and most importantly hospitals as many healthcare personnel are not aware of organ donation. Awareness among police personnel, bureaucrats and politicians is of utmost importance as it helps in achieving the goals of the awareness programs in the region. NOTTO has been trying to achieve a Guinness World Record by logging in one million pledges on a single day. In that initiative, she will be happy to collaborate with all NGOs.

Regarding discussion on collecting organ donation pledges by various organisations, she emphasized that in THOTA act, the first point in the consent form says whether the patient has pledged to be an organ donor. If the patient has pledged and it is known, then the onus is on the family to agree or refuse donation. It is not legally binding but there is an associated moral sanction. Thus, the efforts of organisations who are collecting pledge are very significant and important.

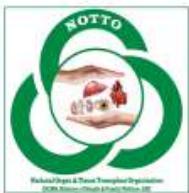
Donor Cards – How NGOs can Login and Upload Forms

A short presentation was given by Mr. Sandeep Rawat, Technical Associate, NOTTO, to explain how NGOs can login and register a donor pledge which NGOs have procured from a person. They can then immediately generate a unique registration ID which can be shared with the person who has pledged with the NGO. As hospitals and NGOs keep sending their queries regarding how to get the registration ID and login into the system at NOTTO this was a very helpful exercise. Anyone needing further help should contact NOTTO.

Dr. Anil Kumar enquired if the donor card had name of the NGO who is issuing it. To which Sandeep replied that the digital donor card issued by NOTTO doesn't have name of the issuing agency. It was clarified by NGOs that only the digital cards issued by NGOs themselves have the name of the issuing NGO at the back.

NGO Login Issues

Several NGOs shared that current process of registration of donors by them on the NOTTO website is tedious and time consuming. NGOs receive pledges on an online form, or in a hard copy of the form. There should be some mechanism to upload the pictures of the pledge form or the online form itself and generate a registration ID, instead of manually logging in the information and then getting the registration ID. The whole process takes in a lot of resources including time, a dedicated person, courier costs (if hard copies are given) etc. So, we must come to a consensus and find a possible way to reduce the cost and time associated with issuing donor cards and rather concentrate those resources on awareness initiatives.



NOTTO Form for the Public

Several NGOs also said that the form on the NOTTO website takes time to fill out (if people do it directly on the NOTTO website) and has a lot of unnecessary details which the public may be averse to filling out and a person may lose interest.

Dr. Promila Gupta said that any suggested changes in the online pledge form can be discussed with NIC. Dr. Anil Kumar said that it is important to understand that the form is not legally binding. He stressed that the form has been designed after pre-testing and thorough study and requested everyone to stick to Form 7 format.

NGO Suggestions

NGOs discussed that they may not want to issue cards to people and would prefer to send their filled-up forms to NOTTO, and NOTTO should send the cards with the name of the issuing NGO. A system for this purpose should be set up. This would immediately do away with the need for NGOs themselves to issue any kind of a digital or hard copy of the donor card. The NGOs duty would be over after uploading the filled-up pledge form.

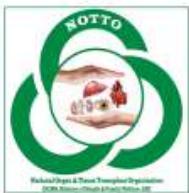
Another suggestion was that the NGOs upload the pledge forms in the form of an excel sheet onto the NOTTO platform, and NOTTO issues registration IDs for all the forms uploaded. For example, most of the NGOs have their own forms so a scanned copy of that form will be uploaded directly through back end to generate registration ID. After this the NGO will issue the common e-donor card/plastic card to whoever has pledged. This would still mean that the NGOs have to make the e-donor cards and email them. (*Following the Conclave, ORGAN India has created a program with a help from a Swedish Engineering student which makes it easy to convert the excel sheet once the registrations have been procured into soft copies that can be emailed. Please contact ORGAN India for further details. Through this program, the process after getting the registration ID has been significantly simplified.*)

Pankaj Agarwal from the NGO A Million Pledges proposed to volunteer to create a program to undertake this process of generating E-Donor card through scanned copy of the pledge form. The pledge form will be uploaded, and rest will be taken care of by the software. He asked whether NOTTO would agree to this proposal. The pledge form can be uploaded, and the registration ID will be generated by the software.

Dr. Avnish Seth, Director FORT asked whether SOTTO had funds allocated for Data entry operator? If yes, then why don't we utilize it? NGOs can mail the excel sheet to SOTTO and then SOTTO can enter it into the NOTTO database. He added that the unique registration ID is important as we don't know how it can be utilized going forward. There is a possibility that such information becomes important the way it is in other countries like Israel.

Dr. Pranay Mahajan from ROTTO Chandigarh said that the registration module in major government hospitals such as PGI Chandigarh etc. has been connected to Aadhar card number. Why can't we link Aadhar card number to donor card in this case? In response, Dr. Promila Gupta said that it can't be done due to the Honourable Supreme Court Order not approving the Aadhar ID to be used as an identity number.

Another Proposal by Pankaj Agarwal in response to Dr. Ramesh's initial point on the Guinness World record was that there be a coordinated campaign to collect a million pledges for NOTTO in November 2020. He said that his NGO, A Million Pledges, would take the lead to create an app and a full program for NOTTO, via which NOTTO and all NGOs would come together and try and reach a million pledges. He will be sharing a proposal with Dr. Ramesh along with a plan of action to make a million organ donation pledges in India a reality.



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To all the suggestions and points made above, Dr. Ramesh replied that NGOs need to follow up with their SOTTOs as funds are given to them for everything. The pledge form must be filled by the NGOs as it will be very difficult for NOTTO to do entries all at once. However, she said there is a provision of mailing excel sheet through A Million Pledges link on NOTTO website.

Regarding unique Registration IDs, Dr. Ramesh added that owing to the digitization that the government is stressing upon we may have HIS system in all major transplant centres. If we can interconnect it then the hospitals where a brain dead patient is identified or the transplant hospitals will be able to ascertain through the online records whether the patient has pledged for organ donation or not.

Regarding the app, Dr. Ramesh asked Pankaj Agarwal to share the proposal with NOTTO, and she requested ORGAN India to put up all the points that all delegates want to convey so that it can be discussed further to find a possible solution.





Discussion Round 2

Organ Donation in Schools & Colleges

Discussion Leaders

Dr. Promila Gupta, Principal Consultant, DGHS, MoHFW, GOI;

Dr. Kulwant Gaur, Founder President, Shine India Foundation;

Dr. Sheetal Joshi, Associate Professor, Nodal Officer for Organ Donation Awareness Activities, Lady Hardinge Medical College

Dr. Promila Gupta said that there is no doubt that in order to create awareness on organ donation it must be taken up in schools and colleges. NGOs should adopt schools in their area so that there can be a continuous discussion on organ donation and not just one event. Once the children are aware, they spread information to whole family. In colleges, awareness talks should be organized in college fests or programs. Short film competitions, poster making etc. should be done.

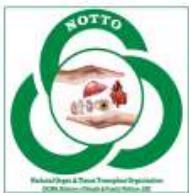
Dr. Sheetal Joshi added that LHMC has taken a lot of initiatives to promote organ donation in the medical college and hospital. Student programs are organized with local NGOs. There are 7 groups in LHMC who are working on awareness such as AIDS, addiction, organ donation etc. Students are enthusiastic and register to form a dynamic group. Workshops are conducted and resources are in-house. Collaborative events are organized where all medical colleges participate. Information delivered by students is authentic and well researched. It gives students an opportunity to bring some change to society. Example - One of her students started awareness program in her hometown in Haryana and made her village people aware about organ donation.

Dr. Kulwant Gaur from Shine India Foundation reflected upon his organisation's work on eye donation in schools. He shared how a 7th grade student motivated her family to donate the eyes of their loved one after death. The student was later felicitated in the school, and till date around 700 schools have been covered by Shine India Foundation. The Directorate of Education issued a notification to all Division schools to conduct an awareness session on organ donation in their premises, organised by Shine India Foundation. Letters have been written to the Government to include a chapter on organ donation in the school curriculum in Rajasthan.

Examples of organ donation topic in education curriculum

Dr. Joshi said that organ donation topic has now been included in the Foundation Course under the new Competency based Undergraduate Curriculum for MBBS students. This has been mandated by the Medical Council of India in the new course and included in the first year of MBBS. The new curriculum, which began from the last academic year, has a course to help students understand the benefits of organ donation, and has guidelines on how to speak to patients or their families on the subject.

Mr. T. N. Panda, from MOTHER, Odisha, said that the Government of Maharashtra has introduced the poem 'Life Goes On' in school curriculum in 2006 and lately in 2018, a chapter has been included on organ donation in school courses. On the request of NDTN, the Maharashtra University of Health Sciences has included it in the undergraduate course for medical students. He has been trying to persuade the Government of Odisha to include a chapter on organ donation in the school curriculum.



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Dr. Pranay Mahajan, Senior Resident, Department of Hospital Administration, PGIMER Chandigarh, ROTTO Northern Region, said that in PGI Chandigarh, a research was conducted which reflected upon a lack of knowledge on organ donation among the nursing staff. So, the National Nursing Institute of Education has sent the proposal to add organ donation chapter in the curriculum to the Indian Nursing Council. He said that the organ donation topic was included in induction program for the interns at PGIMER hospital, Chandigarh. Dr. Promila Gupta added that currently organ donation has not been included at the national level in all Nursing Colleges but the proposal can be considered. Also, she said that organ donation should be included in other general courses too and not just the ones for medical students. Such thought-provoking topics should be included in law courses, humanities subjects, sociology etc. under ethics classes.

Lt. Col. (Retd.) Sandhya Ashok, Transplant Coordinator, Batra Hospital, Delhi, said that this year in the CBSE final English examination question paper for the students of Class 12th a comprehensive passage on organ donation and green corridor was included. She was elated to receive a call from one of the students saying that she could understand the question better as she had attended an awareness talk organised by AORTA (Armed Forces Organ Retrieval and Transplantation Authority) and ORGAN India at her school. Many school students called her to share that they knew all the answers to it because of the awareness talk.





Discussion Round 3

Swap Transplant Registry – Where we are and How we all can coordinate to facilitate this further

Discussion Leader

Dr. Ganesh Sanap, Clinical Operation Head, Apex Kidney Foundation

Dr. Ganesh Sanap spoke about swap transplantation and its significance today. Most of us know about swap transplantation which is generating good number of transplants and helping patients. Apex Kidney Foundation runs a swap registry, awareness initiatives, funds transplants, provides post-transplant medicines etc.

Swap transplant is done for those patients who have incompatible near relatives to donate organs. They come forward and get themselves registered with ASTRA and the organisation finds matches for them by registering them on the swap registry. ASTRA (Apex Swap Transplant Registry) have been in operation since 2011, and has facilitated 80-90 swap transplants to date.

In a meeting at IIT Mumbai, there was a big discussion on swap transplants that hospitals such as IKDRC in Ahmedabad and Medanta in Delhi etc., who are running binary swaps or domino transplantation should come together and form a central registry. Dr. Sanap said that all those running a swap transplant registry can come together and create one big database under NOTTO which will get a boost similar to deceased organ donation program under NOTTO.

Mr. Sandipan Arya (Prabhari Sevadar, Muskan Group) suggested that there should be a swap transplant registry at national level where patient's name is registered for swap transplant so that it helps more and more people. Dr. Ramesh said that she is waiting to receive a communication from IIT Mumbai and a paper from ISOT regarding the points discussed in the meeting on swap transplantation in India, which she has not received yet. Once received, she will take it up with the concerned authorities on how a national level swap transplant registry can be built.

Dr. Geetika Vashisth (Senior Project Manager, ORGAN India) asked what should ORGAN India and other NGOs do in case they receive a query related to swap transplants and registry from distressed patients and their families. She said that ORGAN India receives such requests on their helpline regularly and would like to know how they can be addressed. Dr. Sanap suggested that such calls should be forwarded to him so that further details related to swap transplants can be shared with patients by his team. Since, they are in best position to explain everything about swap transplant and registry it is best that the details of the caller be forwarded to Apex Kidney Foundation.





Discussion Round 4

Innovative concepts for spreading awareness on Organ Donation

Discussion Leaders

Rajesh Shetty, Founder, Rebirth Foundation;

Pankaj Agarwal, Director, A Million Pledges;

Kamal Khurana, General Secretary, Dadhichi Deh Dan Samiti

Mr. Pankaj Agarwal suggested making an interactive mobile application for organ donation. As witnesses are required on the NOTTO form when someone pledges, the app would send all witnesses a message about their pledge and a message asking them if they would like to be organ donors as well. If they say yes, the message is forwarded to next set of witnesses and thus, goes viral. Form is submitted via the app which is directly connected to the NOTTO website where the registration ID is generated. The e-donor card will be downloadable, and a message is posted on Facebook and Instagram that the person is now an organ donor. All this is done automatically in a no-fuss manner.

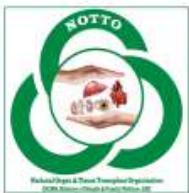
He said that the incentivization and corporate integration are the next steps. It is difficult to raise money through CSR but innovative methods can be used. For example, a company like DHL can for one day write a message to support organ donation on all their parcels.

Content can be put on mobile application which can be used by the teacher to make her class aware of organ donation. The content can be directly played through smart classrooms. Sponsorship can be done with Camlin etc. A collaborative model can be followed where an app can be used by an NGO and can be accessed by the school.

Mr. Rajesh Shetty from Rebirth Foundation spoke about the short movie competition on organ donation organised by them. More than 100 short movies on organ donation have been received by Rebirth Foundation in last 3 years which can be used to create awareness by any organisation. He said that the Bharat Organ Yatra is organised where a volunteer travels all across India talking about organ donation. Many awareness talks especially in college campuses are organised to create awareness known as Rebirth Talks.

Mr. Sandipan Arya suggested that social workers/influencers, who are working for organ donation, should be given an opportunity to be a part of the administrative board or council at SOTTO level to keep the ball rolling and helping the administration to do more work. Nilesh Mandlewala from Donate Life, Pallavi Kumar from MOHAN foundation, Sandipan Arya from Muskan Group and Sunayana Singh from ORGAN India are members of government committees on organ donation. Other NGO representatives should also be included in State Committees across India.





Session 5: Role of Media, Films in Organ Donation Awareness

Speakers

**Badal Rag, AVP – Brand, The Times of India;
Sanjana Agarwal Jain, Flying Elephant Films;
Ambika Singh, Consultant, NDTV**

Mr. Badal Rag said he was happy to be a part of the conclave as the Times of India strongly supports organ donation as a cause. He said that it is good to see that how anyone even if not a core stakeholder in organ donation awareness is able to be a part of the cause by participating in such initiatives. The Times of India, started working to promote the cause of organ donation 7-8 years ago. Even though organ donation is not their only social cause, it is an important cause that they have taken up over the years and on a large scale. After they started their campaign with MOHAN Foundation & Shatayu to create awareness, within a year there was a surge in requests to conduct awareness sessions by people and organisations thus showing anticipated impact. In a nutshell, that is the role of media.

Suggestions, Comments & Queries

In response to a question by Anika Parashar why media doesn't cover causes pro-bono and how cash-strapped NGOs can collaborate with media, Mr. Rag said that media needs collaborators like Kokilaben Hospital or Maruti Suzuki to put in resources for the campaign, as campaigns cost money. NGOs cannot match that. The newspaper has a finite space. Like NGOs, private organisations must sustain themselves too. Resources are required to take the journey ahead over the years and not just one time. He shared that working with MOHAN Foundation and Shatayu has been a non-monetary relationship.

NGOs provide the stories, and the paper publishes what it finds newsworthy. Both parties need to come to an understanding. As regards the interest of the media, the first thing to be identified is whether it is newsworthy and connects with people or not. When green corridor was done for the first time in country, it was a lead story in the newspaper and was covered for a long time. It made for a great human interest and connected deep without any collaborator. Media outlet doesn't just give out information, the story has to have a connect.

Dr. Avnish Seth suggested that concession can be given for publishing obituaries for those who have donated organs.

Dr. Kulwant Gaur from Shine India Foundation suggested that all written material should be drafted nicely and shared with newspapers and media so that it gets published. In Tier 2 and Tier 3 cities newspapers tend to cover everything. So, if good material is available, papers will publish it. The key is to make it attractive. That's what he does in Kota, Rajasthan.

Ms. Ambika Singh said that NDTV has special team projects running such campaigns. It is very important to reach out to the correct team to keep the campaign going as so many stories are important, and it is difficult for a channel to cover everything. It is very important to find the exact journalist/team who covers the topic and reach out to them.

Along with empathetic factors and emotional stories, facts should also be taken into consideration when doing such articles, stories etc. It paints an accurate picture and builds compassion towards the cause. Content can also be published online on the channel's websites.

Ms. Sanjana Agarwal Jain said that there are a lot of issues and not everything can be covered by the media. Since NGOs have all the raw material with them such as stories of hope, emotional stories and information if they are



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packaged well and made available, the media houses will show interest in them. Sanjana added that if NGOs put these well-packaged stories on social media it can go viral and may be picked up by the media. She also said that communication should be simplified, touch heart strings, portray heroes, and show one person's story rather than that of many. Information should inspire people and there should be hope in the end.

Comments & Suggestions

Pankaj asked Sanjana if something specifically can be crafted for creating awareness among young students and in age bracket. Content for them should be more educative and less sensitized. Will it be possible to conceptualize a movie for younger kids? Sanjana said that she can help with the films, animations and infographics for kids.

Lt. Col. (retired) Sandhya Ashok, (Transplant Coordinator, Batra Hospital) said that she had a disappointing experience where a transplant recipient couple's story was not covered by the media even though it was a unique scenario.

Sanjana suggested that in such cases information should be shared with filmmakers and then crafted into stories or, stories can be shot on a good phone and packaged nicely. Ambika Singh said that once again it is important to know the right person in the media house to approach.





Session 6: Kirti Parashar Oration

Speaker

**Dr. K. R. Balakrishnan, Chairman & Director,
Institute of Cardiac Sciences, Director of Heart & Lung Transplantation,
Programme and Mechanical Circulatory Support, MGM Healthcare, Chennai**

This conclave ORGAN India instituted the **Kirti Parashar Oration** in honor of our former Chairperson, Late Mrs. Kirti Parashar. We were privileged to have the first Oration delivered by **Dr. K. R. Balakrishnan, Director & Chairman, Lung & Heart Transplant, MGM Healthcare Chennai**. Dr. Balakrishnan is one of India's most successful heart transplant surgeons and was also Mrs. Parashar's surgeon.

Mr. Vidur Parashar, Trustee, Parashar Foundation introduced Dr. Balakrishnan with a heartfelt note. He said that ORGAN India was created after their mother Late Mrs. Kirti Parashar, who was suffering from a degenerative heart disease, was told that she had to undergo heart transplant surgery. He expressed his gratitude to Dr. Balakrishnan who gave his family another five years with their mother by conducting the successful heart transplant that saved her life. Loved by all his patients and their family members, Dr. Balakrishnan has now become a family member for Parashar and Gujral families, and was a dear friend of Late Mrs. Kirti Parashar. He welcomed Dr. Balakrishnan on the dais to give the first Kirti Parashar Oration.

Kirti Parashar Oration

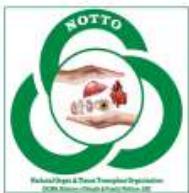
Dr. Balakrishnan shared anecdotes from his interaction with Mrs. Parashar, about her exuberance and zest for life, and how her jovial nature led to a patient becoming a dearest friend. One of the initial patients to get a heart transplant, she waited for a long period of four months before she got a new heart. He recalled his most cherished memory, which was when he received a picture from Mrs. Parashar having good time in Moscow with her friends post her surgery. He said that it's outcomes like hers that motivate doctors to strive to achieve more.

Dr. Balakrishnan went on to speak on the present state of organ donation and cardiac transplants in India. He said that although the Transplantation of Human Organs Act came into picture in 1994, organ donation picked up pace only in 2009. The delay was because of the lack of a well-organised organ donation program in the country.

Heart transplants in India started six years prior to liver transplants, but the challenges are more in terms of getting a heart for transplantation. He spoke about the gradual increase in the number of deceased organ donation in our country over the years, especially in last 6-7 years. It is a subject of study that why more organ donation happens South of the line drawn from Mumbai on the west coast to Visakhapatnam on the east coast. Nevertheless, the number of donations is increasing steadily with close to 750 deceased organ donations in 2018. Roughly, a 100 heart transplants are done in his hospital in a year.

Dr. Balakrishnan shared that the majority of the patients who come for a heart transplant are very sick, and come to doctors in a late stage of the disease. This leads to unfavourable outcomes, and therefore an early referral is important to get good outcomes. One has to keep in mind that changing only the heart doesn't serve the purpose if the rest of the body is not functioning properly. It's like new engine in an old car which won't function well. Waiting list mortality in our country is close to 30% as far as outcomes are considered.

Dr. Balakrishnan pointed out the many challenges that heart transplant teams face on daily basis. One in getting a heart for transplantation, as the rate of deceased organ donation in our country is low. Another is the difficulty faced in



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transporting a heart from one hospital in a city, to another hospital in another city. In order to ensure the comfortable transportation of a heart, an air ambulance has been tried and commercial airlines have been used. Airports have been classified into Tier 1, 2 and 3, and in many places the contact numbers of Air Traffic Controllers are kept handy. Even the contact number of the wives of ATCs are saved in case of emergencies. Work is being done with Indian railways to build massive coaches with intensive care units which could help in transportation of patients. One must remember that if a patient is dying, then even a sub-optimal organ is better than no organ.

The other challenge is to manage the patients coming for transplant, as there is a post-transplant care involved. With a lack of adequate facilities around some transplanted patients, monitoring becomes a challenge. Cost-analysis studies are needed as the cost of surgery varies depending on the severity of the patient's condition.

He said that there is a need for better transport facilities and an optimum organ-care system to increase the life span of the organ beyond 4 hours. There is a need to look into possibilities of a long-term storage system for organs. An advanced HLA matching system will help predict the outcomes. Finally, there is a need to investigate possibilities of sharing of organs within countries in the Asian region which might help the situation.

Dr. Balakrishnan concluded by saying that though the outcomes of heart transplants are improving, there is a need for more funding from the government to support the program. He thanked the Parashar and the Gujral families for inviting him for the oration.

In the end, Ms. Kushla Sahgal, the eldest sister of Late Mrs. Kirti Parashar and Trustee in Vijaya Gujral foundation, thanked and felicitated Dr. Balakrishnan with a plaque appreciating his contribution to the cause of organ donation.





Session 7: Driving Licence and Organ Donation – How NGOs and other States can Implement the System

Speaker



**Pallavi Kumar, Executive Director (Delhi-NCR),
MOHAN Foundation**

Mandated choice which is expressing your wish to be an organ donor on the driving licence or any other official document or identity card was the topic of discussion by **Ms. Pallavi Kumar**.

The United States of America was among the first ones to do this and last year in India, the Central Motor Vehicles (Third Amendment) Rules, 2018 that came into force on April 1, 2018 has given the citizens the option to pledge their organs while applying for driving license. In the Form 6 & 7 of Driving Licence, below the entry "Date of issue.....", the following shall be inserted, namely: "Organs/tissue donorYES/NO".

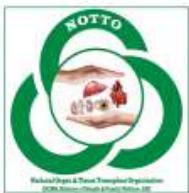
Pallavi stressed that If you offer an individual an opportunity to think about it and make a choice to be an organ donor, people do opt for it and the number is considerably high. She quoted Kelly Nachreiner's story from the USA, who within a week of consenting to be an organ donor on driving licence, donated her organs. After that a law was passed by the then Governor of Wisconsin State. It was made compulsory to conduct a 30 minute organ donation talk during the driving licence taking process, which led to increase in the number of organ donors. Soon after, the donation rate of the state shot up, and then other States in the USA adopted it too.

In 2006, MOHAN Foundation collected 5,000 signatures from people for the inclusion of the clause in the Driving Licence which would allow a person to opt to be an organ donor, and forwarded it to the Ministry of Road Transport & Highways. In 2009 the same were handed over to the Transport Commissioner at a public function. In 2010, a recommendation for inclusion of the organ donation clause in driving licenses was sent to Rajya Sabha standing committee for new transport law. Gift Your Organ NGO has done tremendous work on it in Bangalore.

As far as India's system is concerned, In 2018, Central Motor Vehicle Amendment Rules included a column offering the choice for organ donation in Form 6 and 7 and updated the same on their Sarthi portal software. While this is a significant step, it is not enough, and a representation has been made to Ministry of Road Transport and Highways for the following: Put up motivational posters on SARTHI website to encourage applicants to think positively on organ donation, FAQ's on organ donation for applicants to read should be displayed or written on portal, Offer option to apply for new licence with Organ Donation clause with no extra payment.

Pallavi suggested that all the NGOs working on organ donation should take it up in their respective States/Regions by approaching their local RTOs and requesting the following: Permission to put up informational and motivational posters and messages on organ donation at these offices, Sensitization of RTO officials so that they are in a position to give information and address queries of applicants; Conducting regular awareness sessions at RTOs for the general public; Conducting sessions with driving schools like Maruti etc so that they are aware and feel involved in sending this message.

Mr. Sandipan Arya added that in 2018, Madhya Pradesh Government agreed to include an organ donation column in driving license form but has not been able to implement it. Thus, some push is needed from regional organisations to local RTOs, and also to driving schools.



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Session 8: Effective Utilization of Social Media to Reach Masses and Create Awareness on Organ Donation and Graphics in Organ Donation

Speakers

**Shokey Malik, Founder and CEO, WeBeasts;
Kavita Puri Arora, Thirteen Twenty Productions**

Mr. Shokey Malik stressed the importance of social media in supporting the causes led by NGOs. It helps in branding, fundraising and on-boarding volunteers. It's about telling stories, and not just the facts, and it's used to help NGOs reach out to large number of people. Interactive content forms the most important factor on social media. Compelling and thought-provoking content, use of hashtags to increase reach, checking and responding to questions to ensure regular engagement are some of the points to be kept in mind. Scheduling social media content in advance, use of visuals to drive website traffic and making it easy for followers to donate to the cause are some strategies that should be used.

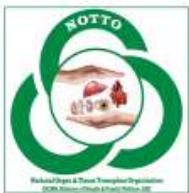
It is also essential to measure the effectiveness of your social media strategy by inserting regular checks and balances. To be most effective, one should follow the STDC framework i.e. See - Think - Do - Care approach on social media and utilize it for maximum visibility and support to the cause.

Ms. Kavita Puri Arora who creates ORGAN India's graphic, posters, reports etc., had several important pointers for all NGOs. In the context of organ donation engaging people is the most important thing in creating awareness in society. Social media plays a huge role to achieve this objective. It is important to identify what qualifies as a good design where awareness campaigns are concerned.

Some pointers to ensure eye-catching and effective graphics are: identify the audience and the ultimate goal; follow a relevant colour palette, perhaps the corresponding NGO's colours; stay away from too much text as it distracts from the message; select the perfect font; select eye catching graphics; stick to 2-3 contrasting colours; reduce the clutter and keep it simple.

Ultimately, she said that - Simple is always the Best - when it comes to graphic design.





Session 9: The Pravin Agarwal Foundation Model – Role of Private Foundations in Facilitating Funds for Transplants

Speaker



**Kankshi Bhavsar, Manager,
The Pravin Agarwal Foundation**

Ms. Kankshi Bhavsar said that The Pravin Agarwal Foundation (TPAF) has been actively enabling liver transplant care for children. There is a high number of paediatric patients who need liver transplants in India and are not able to get access due to associated high cost of surgery. Currently, out of 3000 paediatric liver transplant surgeries, approximately 150 are performed.

Under the leadership of Mr. Pravin Agarwal, TPAF is enabling access to liver care for hundreds of children through financial

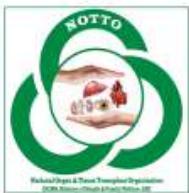
support at an affordable cost, regardless of the family's socio-economic background, so that the transplant becomes affordable. At the moment, the foundation provides financial aid only for pediatric liver transplants.

The Foundation follows a model to bring altogether an ecosystem level change by providing funds for transplant through grants and crowd funding campaigns; by collaborating with hospitals, doctors, funders, and ecosystem stakeholders; by providing a platform for knowledge-sharing through liver-care events and building a database.

A simple process is followed for accessing support for children in need of transplants. The amount of paediatric liver transplant cost to be given by patient's family is fixed at 2.5 Lakhs. The Foundation underwrites all campaigns, taking full guarantee of funding the patient if enough funds are not raised via crowdfunding in the given period of time. Assured risk management by post-operative complication/repeat surgery support is provided to the children. Till February 2020, 140 paediatric liver transplants have been supported.

The Foundation has also formed a patient support network through pre- and post-transplant patient family's meet, quarterly meetings, and WhatsApp groups to keep patients connected to the Foundation and to Doctors. North, West and South Chapters have been formed to enable patient support. The Foundation also has a mobile application which provides a platform for hospitals to collaborate, show funding support or get involved to support the cause.

Ms. Bhavsar requested all the NGOs to contact the The Pravin Agarwal Foundation in case they come across a patient needing help and financial support.



Session 10: Organ Donation Program in the North-East - Success and Challenges

Speaker



Priyanka Borah, CEO, Zublee Foundation

Ms. Priyanka Borah mentioned that the Zublee Foundation is the only NGO in the North-East region of India (comprising eight states) working to raise mass awareness on organ donation and to encourage people to support Deceased Organ Donation. Tremendous success has been achieved via its initiatives such as public education talks, music concerts, motorbike rallies, marathons, walkathons, cycle rallies and street shows.

More than 2500 people have pledged to be an organ donors. They have been awarded by the Government for their contribution in the field of organ donation. One of the challenges faced by the organisation is language barrier while interacting with local communities especially tribal groups as most of them communicate in local language. Other challenges include ensuring support from government and private institutions while implementing initiatives. Lastly, financial constraint poses the biggest challenge as far as organ donation awareness is concerned.

Session 11: Organ Donation Awareness in Odisha - Success and Challenges

Speaker



T. N. Panda, CEO, MOTHER

Mr. T. N. Panda from MOTHER shared the successes achieved in Odisha through consistent efforts over a long period of time. He was thankful to the Government authorities for their help.

He said that it took a long time to start the program but finally all their efforts are bearing fruit. Odisha has finally begun its deceased organ donation program in November 2019 and till February 2020, two donations have already taken place.



Session 12: Organ Donation Awareness in Indore , Madhya Pradesh

Speaker

**Sandipan Arya, Prabhari Sevadar,
Muskan Group**



Mr. Sandipan Arya said that the Muskan group has been engaged in the social cause of organ donation in Indore for almost 15 years with the support of their team members and volunteers. They have been actively working to promote cornea donation and organ donation in the city.

He informed everyone that Indore was the first city in the country to follow a single window permission system in organ donation, which means that the permissions related to organ donation and allocation were sought from one centralized point of contact instead of different departments, as per the Notification issued by the local

administration.

Indore was the first city to issue a notification permitting arrangement of post-mortem in Medico-Legal Cases, in order to support the families who choose to donate organs of their family member after he/she is declared brain death, in the organ retrieval centre itself. Two members among the next of kin of the deceased donor family are provided with health insurance up to 5 lakh for a 5 year term.

More than 10,000 corneas have been retrieved and donated successfully in Indore. Indore's skin bank is the second largest skin collection bank in India. Muskan group has undertaken workshops, talks, sessions and other initiatives to promote the cause of organ donation in Indore through a joint venture with the Indore administration.

Sandipan Arya suggested that all the NGOs should come together and visit each other to conduct awareness sessions in other states in order to complement each other's work and make organ donation awareness a success.





Session 13: Panel Discussion on World Transplant Games, India's Transplant Games and Role of NGOs

Speakers

**Karhun Nanda, Heart Recipient, World Transplant Games 2019 participant;
Ankita Srivastava, Liver Donor, World Transplant Games 2019 participant;
Dr. Navdeep Bansal, PGIMER Chandigarh**

Mr. Karhun Nanda said that at the World Transplant Games 2019, held at Newcastle Gateshead in United Kingdom in August 2019, a total of 59 countries participated with more than 3000 participants from all over the world. India had a contingent of 14 athletes supported by their team manager Reena Raju, from the Reena Raju Light a Life Foundation.

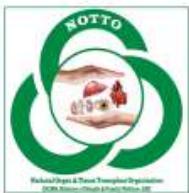
Reena Raju, a double heart transplant recipient, was India's first woman organ transplant recipient to participate in World Transplant Games held in Spain in 2017. She was the Indian flagbearer in the World Transplant Games 2019. In the latest edition of World Transplant Games, India was represented by 14 athletes including 11 organ transplant recipient and 3 organ donors. Participants for World Transplant Games 2019 were Amar Nath Tanwar, Haryana, Kidney recipient; Vishnu Nair, Haryana, Kidney recipient; Anil Srivatsa and Arjun Srivatsa, Karnataka, Kidney donor and recipient; Ankita Srivastava, Madhya Pradesh, Liver donor; Balveer Singh, Uttar Pradesh, Kidney recipient; Kishore Suryavanshi, Maharashtra, Kidney recipient; Digvijay Gujral, Madhya Pradesh, Kidney recipient; Karhun Nanda, Haryana, Heart recipient; Davis Jose Kollannur, Kerala, Double kidney recipient/cancer survivor; Raghavendra Nagaraj, Chennai, Liver recipient; Praveen Kumar Rattan and Roopa Arora, Chandigarh, Liver recipient and donor; Sridhar M.J., Karnataka, Kidney recipient.

The United States contingent had 125 participants as compared to 14 athletes in Indian contingent. They were a highly professional team with proper support from the government. They had a team of physiotherapist and managers whereas Indian team was self-funded with no support from the Government at all.

The World Transplant Games are affiliated to Olympic Committee and are, till date, not officially recognised in our country. Both transplant recipients and living organ donors participate in the games. The event at Newcastle Gateshead in United Kingdom had all the major games and was well coordinated. It was an amazing experience and Karhun's interview was luckily covered by BBC.

Unfortunately, in India, no one knows about the transplant games. Recognition for the games by the Government is paramount, as lack of recognition makes it difficult to get corporate sponsorship for athletes.





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Dr. Navdeep Bansal shared that the transplant games in India started in 1981 and were organized by PGI Chandigarh. Recently, another edition of Indian Transplant Games was held in Chandigarh organised by PGI Chandigarh. Donor families are also invited for this event so that they can observe how organs donated by them help someone live a healthy and happy life. The games are held annually and are a big success. There is a good media coverage too.

Ms. Ankita Shrivastava said that they faced many challenges. She said while the experience to participate in the games was great, it was unfortunate that there was a huge difference between the number of participants in the other countries and Indian contingent.

Ankita added that she had approached many corporate companies to raise some sponsorship funds, but no one came forward to sponsor the Indian contingent or her individually. A few athletes managed some sponsorship but the majority expenses were taken care of by themselves. She said she met Shri Karen Rijiju ji to discuss about the recognition and inclusion of transplant games at par with other official games recognized by the Ministry of Sports but no concrete outcome was achieved. There is a need to constantly follow up on the same with the higher authorities and come together to give a strong push for it under the aegis of NOTTO.

Suggestions and Ideas

Dr. Ramesh asked Karhun Nanda to submit a proposal for funding and help for Indian athletes to ROTTO Chandigarh as they already hold the transplant games and they could help the Indian Contingent for the next games in a proper way. She said that once the proposal is submitted then NOTTO will take it up further.

Dr. Bala said that it's not easy for a common organ recipient or donor to spend money for travel and training for games. No government support makes it difficult for those interested to participate. He said team members should try and contact pharma companies like Novartis etc. He showed solidarity with the Team and said that everyone should contact pharma companies to sponsor the team. He also offered to contact them personally on behalf of Team members for next edition of games.

Pankaj suggested that the corporates like Nike etc. should be approached to get sponsorship. There should be a good story and people will come forward to support adventure sports. But Ankita said that because of lack of recognition, this was not possible.





Conclave Summary and Action Points

Donor Cards

Dr. Vasanthi Ramesh lauded the efforts of NGOs towards collecting donor pledges and stressed that it is very important. Difficulties faced by NGOs in sending out donor cards were discussed.

- Feasible changes to the NOTTO pledge form to ensure an efficient mechanism will be shared with NOTTO by ORGAN India after consultation with all NGOs.
- It is labour intensive and expensive for NGOs to register pledges and send donor cards. Pledge data can be shared by NGOs with their respective SOTTOs. Utilization of funds given to SOTTOs for employing a data entry operator to register pledges and send out donor cards needs to be explored.
- Shifting from plastic donor cards to electronic donor cards
- Pankaj Agarwal from A Million Pledges volunteered to create a program for NOTTO for generating e-donor cards. He will be submitting his proposal to NOTTO.
- ORGAN India has since designed a computer program that converts data from pledge form into electronic donor cards so that process of sending them out is simplified. (Please contact ORGAN India if you wish to use this program)

Setting a Guinness World Record for Collecting Pledges

Dr. Vasanthi Ramesh wishes to reach one million pledges leading up to Indian Organ Donation Day 2020 and set a new Guinness World Record. She suggested that all NGOs collaborate with NOTTO to come up with creative ways to achieve this goal.

- Pankaj Agarwal from A Million Pledges will submit a proposal to NOTTO to achieve Dr. Ramesh's goal. He wishes to create a mobile application and a full program for NOTTO by which NOTTO and all NGOs would come together and try to reach a million pledges.
- There needs to be a coordinated campaign to collect a million pledges in November 2020. NGOs are requested to come up with ideas on how they can help execute this and submit them to NOTTO, once NOTTO rolls out the plan.

NOTTO Website to Give Recognition to NGOs

It was discussed that NOTTO should, after due diligence, mention the names and contact details of the NGOs working in this space on its website under the relevant section. This recognition is important for NGOs as they look to raise funds for expansion of their initiatives.

- A proposal for the same will be shared with all NGOs for their approval, before being shared with NOTTO.

Organ Donation Awareness at Medical Colleges & Other Higher Institutions

- NGOs to follow up with medical colleges in their respective regions whether organ donation module is being taught as part of the new notified curriculum or not, and report to NOTTO if any discrepancy is identified. NOTTO will take it up with the concerned medical college and ensure that the curriculum guidelines are followed.
- NGOs should try to get organ donation included in other courses. It is important that topics such as organ donation should be included in non-medical courses such as law courses, social sciences or under ethics classes etc.



Organ Donor Status on Driving Licenses

Ms. Pallavi Kumar from MOHAN Foundation talked about inclusion of organ donor status on driving licenses and asked for all NGOs to push for its inclusion with RTOs in their region.

- All NGOs to approach local RTOs and ensure that IEC material such as posters, brochures, pamphlets are available.
- NGOs should also make this material available in driving schools so that learners have no choice but to watch a short film on organ donation as a part of their learning material.
- Module on organ donation to be included in driving test.
- Implementation of the above needs to be ensured as Mr. Sandipan Arya mentioned that Madhya Pradesh government had issued the guidelines on including organ donation column in the driving license form in the state, but it hasn't yet been implemented.
- Ms. Pallavi Kumar from MOHAN foundation is willing to help those needing details on how to proceed.

Representation on State and National Level Advisory Committees

- Representatives from NGOs working on organ donation and other influential members of society should be a part of the regional government's committee working on organ donation in an advisory capacity as they already have a lot of experience with awareness initiatives. They can bring more creativity and innovative ideas to further the organ donation program in the state.

Use of Radio for Creating Awareness

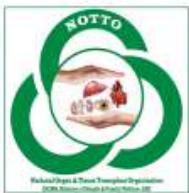
Radio as a platform for creating mass awareness should be taken up as it reaches everyone in all corners of the country. Everyone listens to the radio, especially in rural areas. It is a cost-effective medium to create awareness. It will help tremendously in propagating the information.

- NOTTO Director Dr. Vasantha Ramesh urged all NGOs to reach out to Community Radio Stations in their region to take the message of organ donation directly to the people
- NGOs should propose shows on organ donation to their closest community radio stations.
- ORGAN India would be happy to help anyone who wants to get started and share information on the equipment required, ideas for programs, setup etc.
- Community Radio Association currently has 289 stations across India. Mr. M.S.H. Beg (Treasurer, Community Radio Association) is ready to help all NGOs in this regard.

Swap Transplant Registry at National Level

A Swap Transplant Registry is needed at the national level so that swap transplants can become an effective way of reducing the waiting list. NOTTO is awaiting communication from IIT Mumbai and a paper from ISOT regarding the points discussed in their meeting on swap transplantation.

- In case anyone receives a query on swap transplant, Dr. Ganesh Sanap (Apex Kidney Foundation) suggested that such calls be forwarded to the Apex Kidney Foundation so that they can be provided the correct information on swap transplant and a swap can be set up.



Innovative Methods for Outreach

- As it can be difficult to raise money through corporates directly, it was discussed that NGOs should instead suggest incentivization. For example, a logistics company like DHL can, for one day, write a message endorsing organ donation on their parcels, leading to lakhs of people being educated in one go. Or a big store could put a message on organ donation on their packets for a month. Such collaborative campaigns should be actively pursued by NGOs.
- Mobile Application for School Outreach: Content can be put on mobile application which can be used by teachers to educate her class on organ donation. The content can be directly played through smart classrooms. Sponsorship can be got through companies making products for students, like Camlin etc. Mobile apps can further be used by people to pledge.
- Special films/infographics etc. should be made for younger children. These will have to be carefully thought out and presented so they are appropriate for small children. NGOs can work closely with filmmakers and artists to create these. Sanjana Agarwal from Flying elephant Films said she could help with this.
- NGOs can propose their District Administration or State Authorities to replicate the new Haryana's Angdaan Mahadaan Program modelled on their successful Beti Bachao Beti Padhao Program which has seen good results in the State. District's Deputy Commissioners, the highest administrative authority in the district, can be approached to propagate the awareness program in the specific District.

Awareness and Outreach Mechanisms

- It was suggested by several eminent speakers that NGOs should adopt schools, small hospitals and colleges and interact with them regularly rather than doing just a one-off awareness drive. This will help build support for the cause and keep people interested in the subject.
- NOTTO Director suggested in her opening speech that increasing awareness amongst hospital staff, bureaucrats and politicians would be of tremendous help as everyone needs to understand the importance of organ donation for the movement to go forward.
- Training of ASHAs, ANMs, Anganwadis, social workers and volunteers should be undertaken by NGOs as it is not possible for NGOs to reach everyone in faraway areas. Mass awareness can be increased only if there are enough people trained to give lectures extensively in one region. ZTCC Pune has done so in collaboration with Rebirth.
- Foundation and ORGAN India has done something similar in Gwalior, Ludhiana and Dharamshala.
- Local religious leaders should be roped in as their words carry a lot of weight.

Media Strategy for NGOs

Role of Media & Films in promoting organ donation was discussed. It was pointed out that a press release should be drafted in an interesting way by NGOs and shared with the newspapers and media so that it gets published easily and in a timely manner.

- As any campaign has certain costs attached to it, it would be a good idea to find a sponsor. If an NGO has no sponsor or funds, they can pitch to media houses to have a non-monetary association (as TOI has done for its campaign where NGOs provide the raw material and get mentions).
- A suggestion was made that concessions be given for publishing obituaries of those who donated organs. This should be formally proposed by us to all newspapers and publishing houses.
- It is much easier to publish in smaller towns and cities as there are many local newspapers that cover a wide range of topics. So, if the material is attractive, packaged well and made available, newspapers will publish it. The key is how the story is presented to the media. NGOs have all the raw material with them (such as donor/recipient stories, information), they just need to put some thought into packaging it and reaching out to the media.
- It is also very important to reach out to the correct team in any media house in order to get coverage. Approaching the wrong journalist may see an interesting story being ignored. Finding the exact journalist/team who covers this topic and reaching out to them increases the chances of a story being carried.



Social Media and the Role of Graphics

Social Media is a highly effective, low cost and creative tool to reach out to millions of people.

- It was suggested that interesting, interactive content is the most important factor on social media and elicits greater engagement from the audience. Compelling and thought-provoking content should be used.
- The use of hashtags to increase reach is a must.
- Check and respond to queries on social media to ensure regular engagement.
- Use of interesting visuals helps drive website traffic to the page.
- It is important to identify what qualifies as a good design. Identify the audience and the ultimate goal, follow a relevant colour palette, stay away from too much text, select the perfect font, select eye-catching graphics and stick to 2-3 contrasting colours. Finally, reduce the clutter to keep it simple.
- Making it easy for followers to donate to the cause should be taken into consideration. This way we can raise funds through our work.

Indian Transplant Games & World Transplant Games

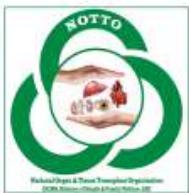
Indian Transplant Games are organised annually by PGIMER Chandigarh where transplant recipients and organ donors participate in different sports events. World Transplant Games are organised every two years, with the last one held in 2019 where 14 Indian athletes participated. It was one of the most successful for India as the contingent won many medals.

- The World Transplant Games (WTG) are affiliated to International Olympic Committee but have not been officially recognised in our country. This means there is no support provided by the government to our athletes. NGOs and NOTTO to work on a proposal for their recognition.
- NGOs should reach out to recipients and donors whom they know would be interested in participating in these games and help them train. For any information related the World Transplant Games, they can contact Anil Srivatsa from Gift of Life Adventure or Karhun Nanda. Those interested in participating in the Indian Transplant Games are requested to contact Dr. Navdeep Bansal from PGI Chandigarh for participation in the games and for any other information.
- Karhun Nanda to submit a proposal for helping Indian athletes at WTG to ROTTO Chandigarh as they already hold the Indian Transplant Games and they could help the Indian Contingent for the next games in an official capacity. NOTTO will further take up once that is done.
- Members should contact pharma companies as it's not easy for most organ recipients or donors to spend money for travel and training for games. No government support makes it difficult for those interested to participate. Dr. Balakrishnan also offered his help in contacting pharma companies on behalf of the team members.

Funding for Transplants

Lack of funds for a transplant is something that affects a large part of our population. Even if they manage to get a transplant, the patient is then unable to afford their post-transplant care, including immunosuppressant drugs. NGOs frequently receive queries regarding funds for transplants.

- Crowdfunding is one of the most popular ways to raise funds. The patient's story and emotions need to be packaged in such a way that people are moved to donate.
- Some private foundations are also taking the lead. The Pravin Agarwal Foundation (TPAF) is enabling access to liver transplants for hundreds of children. Currently it is only for paediatric liver transplants. Kankshi Bhavsar asked NGOs to get in touch with TPAF in case they come across a patient needing help.
- NGOs and NOTTO to work on a proposal to bring transplants under various government schemes.



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Sharing of IEC Material & Working Together

- Sharing of IEC material is encouraged. Organizations have unique films, posters, and other IEC materials that they have created and that can be shared with all the NGOs. ZTCC Pune and Rebirth Foundation, ORGAN India, MOHAN Foundation, Zubilee and many others have material that they wish to share. Organizations are requested to reach out.
- NGOs should also get together and promote certain hashtags on social media at given times and have collaborative campaigns so that organ donation trends.
- NGOs are encouraged to keep a list of all NGOs and their representatives in various regions handy so that if a call for help/session comes through then they can direct it to the respective NGO in the region.
- **Regular monthly video conferences between all NGOs will be set up by ORGAN India so that we can all discuss the latest developments and move forward collaboratively.**



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