



THIRD COLLABORATIVE CONCLAVE for Organ Donation





THIRD COLLABORATIVE CONCLAVE
for Organ Donation



Coming together
is a beginning
Working together
is progress
Staying together
is success



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NOTN
NATIONAL ORGAN DONOR TRANSPLANTATION NETWORK

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"From each according to his ability
To each according to his need"



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THIRD 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 strategizing 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 Transplantation Organization (NOTTO), has made sincere efforts to bring all the regional NGOs and other stakeholders working on organ donation on one single platform.

ORGAN (Organ Receiving & Giving Awareness Network) India, an initiative of the NGOs Parashar Foundation & The Vijaya Gujral Foundation, organized the Third Collaborative Conclave for Organ Donation, under the aegis of NOTTO. The conclave was held with all the NGOs working in the field of organ donation on November 29th, 2018, at Juniper Hall, India Habitat Centre in New Delhi from 9am to 6pm.

ORGAN India firmly believes that a combined force of all organisations 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 even known to each other or the government.

The Collaborative Conclave has become an essential annual event where the national and regional, government and non-government stakeholders come together to discuss and identify the issues, challenges, possible solutions, and the scope of work going way forward in the ecosystem of organ donation. It enables addressing the concerns of one and all under one umbrella and 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 sharing achievements and best-practices with govt. and others
- 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.



THIRD COLLABORATIVE CONCLAVE for Organ Donation



This year the Conclave was inaugurated by our Chief Guest, Dr. Vasanthi Ramesh, Director, NOTTO, DGHS, MoHFW, GOI. Dr. Promila Gupta, Principal Consultant, DGHS, MoHFW, GOI graced the occasion as a Special Guest. Dr. Harsha Jauhari (Technical Advisor, NOTP, DGHS, MoHFW, GOI), Dr. Anil Kumar (Additional DDG, NOTP Program Officer, DGHS, MoHFW, GOI), Dr. Sanjay Agarwal (Professor & Head, Dept. of Nephrology, AIIMS) and Dr. Vipin Kaushal (Nodal Officer, ROTTO Chandigarh) were some of the prominent government dignitaries present at the conclave.

The conclave was attended by around 70 participants from over 13 NGOs and other stakeholders working on organ donation all across India, from states such as Assam, Maharashtra, Gujarat, Rajasthan, Karnataka, Tamil Nadu, Madhya Pradesh, Uttar Pradesh, Odisha, and ROTTO Northern region team from PGI Chandigarh amongst others.

This year representatives from following NGOs from different parts of the country participated in the conclave – MOHAN Foundation, MOTHER, Shine India Foundation, Dadhichi Deh Dan Samiti, A Million Pledges, Zuble Foundation, Apex Kidney Foundation, Muskan Group, Kiran Foundation, Light a Life Reena Raju Foundation, Gift of Life Adventure, NNOS Foundation, and Mindsparks Foundation. Medical professionals from Lady Hardinge Medical College and Safdarjung Medical College & Hospital also participated in the conclave.

There were some new faces at the conclave which made it a more diverse and interesting event. Representatives from ROTTO Chandigarh, Kiran Foundation (Bhopal, MP), and Mindsparks Foundation (Lucknow, UP) attended for the first time. Anil Srivatsa, an organ donor himself, from Gift of Life Adventure who works tirelessly to help organ donors and recipients was present and the indomitable Reena Raju, a double heart recipient and Founder of Light a Life Reena Raju Foundation made huge effort to be present at the conclave.

Welcome Note



Ms. Anika Parashar, Chairperson, Parashar Foundation

The day began with a heartfelt tribute to Late Mrs. Kirti Parashar by the Chief Guest Dr. Vasanthi Ramesh, Dr. Harsha Jauhari, Mrs. Eeda Gujral Chopra (Trustee, The Vijaya Gujral Foundation), and other dignitaries. Ms. Anika Parashar gave a welcome note and thanked everyone for coming together for the Third Collaborative Conclave. She also welcomed and felicitated Dr. Vasanthi Ramesh, Director, NOTTO, DGHS, MoHFW, GOI. After the address, she requested Dr. Vasanthi Ramesh to say a few words and open the conclave.





Inaugural Address



Dr. Vasanthi Ramesh, Director, NOTTO DGHS, MoHFW,GOI

Dr. Vasanthi Ramesh, Director, NOTTO, thanked everyone for the enormous work being done by all the NGOs on organ donation. She said that knowing the culture of the people around and the language of the message acceptable to all, the local NGOs have a leverage to carry forward the work in their areas.

She emphasised on the point that the government organisations, the non-government organisations, the public, the social media, the influencers,

the civil society, the haves and have-not, the literate and the illiterate, we all have to be together in this cause. Organ failure is a common problem and can affect anybody irrespective of race, religion, cast, creed, and wealth or otherwise and that is why we all have to be together in supporting this cause.

She stressed upon the fact that, there are a lot of areas where work can be done in addition to what has already been done till now. The focus needs to shift on post-operative follow ups after an organ transplant. That's when the results of the transplant would speak for themselves. There might be cases where people travel from far off places for the transplant and thus there should be sufficient knowledge among the local health professionals to at least take care of the patients in the post-op period. She advocated forming the support groups of transplant recipients of different organs and also of donor families to figure out what are the challenges these people face, and how can all the NGOs support them.

Dr. Ramesh ended her speech by saying that all NGOs have a role to play within our own sphere and areas. We should collaborate without any fear and act together to take the work on organ donation to great heights, so that in future India is at par with countries like Spain and others in terms of organ donation rate.





Session 1: Ethics and Rules in Organ Donation and incentives for donor families or organ donation pledge takers

Speaker



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

Rules in Organ Donation

Under the Transplant Act, Rules have been well defined, self-explanatory and must be read by everyone. He shared that the Act was donor specific, defining who can donate and how etc. Now, the shift is to the recipient as well. There has to be a room for change in the rules, always. It takes a long time to change laws but rules can be revisited easily and edited accordingly.

Ethics involving Incentivization for the family members of the Deceased Organ Donors

Dr. Jauhari began by saying that if we were to talk about Individual ethics and Collective ethics; whom does your body belong to? If I say I want to donate organs while living, I can't? Do I own my body? Is my body mine? I can donate my body but it's not my body to give. I cannot sell my body, cannot sell my organs, why? Society says no to it. Why? There is a conflict between your desire and that of society when it comes to ethics. Selling your body for prostitution is illegal and immoral but at the same time selling your body for research with consent to a company without knowing the outcomes is fine. Whenever you raise any issue in a way that leads to deviation from collective ideas, immediately there is a storm.

He said we need to understand the difference between inducement and incentive. Inducement is I will pay you if you do this. Inducements are in various forms and are not acceptable. It is implied in master servant relationship that if master gives kidney to servant there is no inducement. But if employee gives kidney to his master out of love for him, there has been obviously some kind of positive or negative inducement.

He explained his point with the help of examples such as cricket players get awarded for winning a match, a doctor is awarded for saving someone's life or armed forces personnel are awarded for doing their duty. Even though it is their duty and job to do what they did, still they get an award in recognition for doing their job. You are giving them something in acknowledgement so that others are inspired to do that as well.

Similarly, we need to honour our donors. There is a lot of physical, emotional trauma associated with both types of donations. Living donors are coming forward to donate an organ while alive. Once she/he gives an organ, nobody thinks of him or his family. He is just mentioned as a donor and left without care. Is that fair? Same is the case in cadaveric donors. Many are sole breadwinners from middle or low middle class. Are they expected to give some parts of their bodies and get nothing out of it? Because they are supposed to be noble and altruistic?

Every single person in the chain gets something out of it because that's their job, doctors, hospitals, and patients who get new lease of life. They get happiness and so much that goes with it. This donor's family who has been brought to the street can't get anything because he is noble. Instead, he should be honoured and this is why we have been trying for past one year to plan and come to a consensus to give some social support in some way to those who give consent for organ donation while they lose their loved ones.

Support to Families of the Deceased Donor

It is inherent in the act that the government can set up a fund under the act. A proposal has been made and is under consideration. Now, the question arises what are we looking at giving?

The deceased donor can be declared a person of importance and the family can be given a card or a certificate which



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should give some percentage points in getting admissions in schools, colleges, getting job, medical treatment, getting reduction in loan rates etc. A Living donor on the other hand can get 50% concession on travel charges, and any problem arising out of donation should be taken care of for lifetime.

Ms. Pallavi Kumar raised a query to Dr. Jauhari regarding incentives asking that why we are having this discussion, whereas across the world there have been no incentives for donation. Should we actually have it looking at the complex structure of our country? Donation is something that the family has to decide and do altruistically. She raised a concern that there are cases where sole earning member of the family dies in a road accident but is not an organ donor, as opposed to other case where the accident victim is an organ donor, then how do ethics justify differentiation in incentives in these two cases. Similarly, concerns were raised by her about the way a conversation between the family and a coordinator will turn out. What if the conversation becomes more towards inducement rather than incentives?

Dr. Jauhari replied that following quote should be noted – “Altruism doesn't sit easy on an empty stomach.” One cannot be noble when they are starving. If someone is doing some good, you make him feel good about it. Honour them for doing well. There will be clearly laid terms. We need to think about Indian solutions, about ourselves and make our own rules. Create our own solutions, follow our own program. We have one of the most extensively laid documents in the form of rules and if needed, further extensive rules should be laid down.

Dr. Ramesh added that the same situation came up in ISOT conference too. It was discussed that the transplant coordinators are facing this issue where families ask about what is there in it for them; they want to know their benefits. They have people who have done donation in past coming and asking them that what they will get in return if the rules change for a donation done retrospectively.

Dr. Anil Kumar added and clarified that the term what has been proposed for the mentioned purpose is benefit and not incentive. If you look at the complete process, people are making money and there is no doubt in that. Surgeon is making money, hospital is making money, recipient gets organs so it is said that you are using emotions to make the person believe that he is doing some good in donating organs, you are using the emotions to make donation happen, but what benefit you are giving to the family of the one donating organs and thus saving so many lives.

Dr. Smriti Sharma from Dadhichi Deh Dan Samiti added that there is a huge section of people coming forward from both affluent and non-affluent section of the society who donate their body and organs only for the altruistic purpose without any benefits or incentives. People do it voluntarily and they are proud of it.

Mr. Pravas Acharya from Body and Organ Donation Initiative, Odisha shared that they have conducted a study in Odisha from the pledge data available with them for 18000 pledges. They found that most of the pledge takers, 62-63%, are women and around 70% of pledge takers come from middle and low income groups. Out of that 1400 Body Donation pledges most of them come from professions such as teachers, lecturers and none from the elite professions or from affluent people. This reflects a clear divide.





Follow Up Points

Anika Parashar (Chairperson, Parashar Foundation) added a concluding statement that, organ donation needs to be a larger cause driven by your heart, your emotions and your need to be kind. However, there are certain realities of our country which Dr. Jauhari has brought to light that there is a larger poorer fraction in our country. Now, someone else said that it doesn't actually matter in terms of benefits, incentives etc., as people are still donating altruistically despite the fact that they are not financially well off and they don't get an additional benefit. So, this is a little bit of debate.

She added that she agreed with Dr. Jauhari that if we are to make a cultural shift faster, it maybe that we will have to look at some kind of a benefit as quoted by Dr. Anil Kumar as well. It's not that there isn't any movement, however if we want some larger and rapid shift, maybe our thought process has to be a little dramatic.

Dr. Koushal added that there could have been option of an insurance scheme or something. Though Ayushman Bharat has started there is no scope for organ transplantation and current scheme doesn't address this aspect. We need to do research on who is donating more, whether they are the affluent people or the poor people in the society and whether we should be giving them any benefit in return.

Dr. Jauhari concluded that we have to choose the direction we want to go. We have to move. Every year while we are debating, people in millions are dying. We don't want that. We can make a change, take a bold step, not illegal, immoral or unethical, take views into account but you have to think along those lines. People have to come together. Then gradually sharp edges smoothen.





Session 2: Success story of ROTTO Northern Region

Speaker



Dr Vipin Koushal, Nodal Officer, ROTTO, Chandigarh

Dr. Koushal shared statistics and success story from PGIMER Chandigarh's Transplant program. PGIMER is doing one of the best cadaver organ donation programs in the northern region. Statistics say that of all organs transplanted, the Kidney transplants have been the maximum number in PGIMER. The success of the program is attributed to various reasons from a good team coordination to the hard work right at the grassroot level.

The reasons for the success of the program at PGIMER, as shared by him, are:

- Committed leadership. Director and Medical Superintendent of the hospital along with a dedicated team are involved in coordinating donations and transplants..
- Multi-pronged media friendly IEC strategy, Media has an important role to play because if positive stories are shared they change the mindset of the people towards organ donation.
- Active and passive surveillance with real time information flow. Transplant Coordinators are always moving around in the trauma center.
- Flexibility in donor selection leading to increase in donor pool.
- Donor being maintained even in triage area ensuring better quality of retrieved organs.
- Regular review meetings for stock taking and feedback prompting immediate redressal of issues, if any.
- Good relations with the traffic police, airport authorities, and others for smooth conduct of green corridors.
- Facilitating post-mortem even at odd hours/holidays/Sundays, saving inconvenience and time for donor families.
- Free transportation facility for donor as an expression of gratitude to the donor family.
- Recognition of donor family's noble gesture by media visibility and felicitation. They support the family members whenever they visit the hospital.
- Ensuring smooth coordination for brain death declaration. In PGI, brain death declaration committee is voluntary and consists of one hospital administrator, one treating doctor, 2 empanelled doctors which could be a neuro physician or an intensivist.
- Latest equipment and continuous training which include CMEs, training of staff, research studies, sensitization of diagnostic staff.
- Creating a difference by building enabling environment with consistent & aggressive awareness campaign in the catchment area and on social media.



Session 3: Discussion over the questions and concerns raised by all the participants addressed to the technical experts present in the esteemed panel from MoHFW

A) Challenges in post-mortem, police coordination in MLC cases and discussing organ donation with grieving family

Topic A1

Dr. Vipin Koushal from ROTTO highlighted that it is very difficult to get police in the loop for organ donation. They get into the problem as per the Act. As most of the brain death cases are medicolegal cases, it is covered under the Act which talks about the possession of the body. Possession is with the police, and when brain death is declared, it is already very late and it takes lot of time to coordinate everything. By the time everything is done, it's too late to coordinate organ retrieval and donation. PGI Chandigarh gets cases from different northern states, with different police working there, and they have different information about the Act. So, there is a need to take the police into the loop and plan accordingly.

Expert Comments

Dr. Jauhari replied, like most of the other medico legal cases, the police is only concerned if there is an unnatural death. They want to know the cause of death. So, medicolegal autopsy will happen in these cases for sure and the police will want the exact steps followed as per the Act. There is no way out of it.

Dr. Ramesh added that Dr Koushal was talking about the lack of cooperation from other departments, specifically police. Basically, we need to have inclusive approach including bureaucrats and to some extent politicians. If the program has been successful in record time in Tamil Nadu and Indore, it's because of involvement of bureaucracy and to an extent politicians and strong political will. Official orders have been passed to facilitate transplant activities and to ensure organ donation in these states happen smoothly.

Pallavi suggested that we have to also educate and befriend police department by conducting awareness sessions and following confidence building measures by regular meetings.

Dr. Rakesh Bhargava from Bhopal shared that they have lot of support from the administration and bureaucracy. Two SDMs are always present in transplant centre hospitals and police is also supportive. Other than this, a letter has been issued to all 52 districts by the commissioner that on 26th January every year the donor families should be felicitated and honoured in each district. Similarly, in another case the donor's body was handed over to the family with so much respect and honour that it became big news and people were inspired by it.

Dr Jauhari said for post mortem doctor, speed and time is not important but for organ donation it is. So, in the operation theatre, the person who is to perform autopsy should be physically be present so that the autopsy and retrieval can be done simultaneously, without any delay and inconvenience.

The surgeon should show the organs to the post-mortem doctor that they are not damaged. This requires good faith between the doctor retrieving organs and the post-mortem doctor. You take it out and hand over the body to the person to continue with the autopsy. It should be done as soon as possible and the body should not be wrapped or cut twice.



Topic A2

Mr. Sandipan Arya requested if an order can be passed at the national level for all the regions so that post mortem can be conducted inside the operation theatre only in the cases where organ donation has to take place. He requested NOTTO to look at the procedure and guidelines being followed in Indore and if possible, it should be replicated at the national level so as to make this whole process smooth and donor family friendly.

He said that usually transplant coordinator is questioned by the family about the time that the body will be handed over to them after donation. It is very difficult to give a set time period in cases of MLC where post-mortem needs to be conducted. The state govt. of Madhya Pradesh has passed special orders giving permission to facilitate and conduct post-mortem in the operation theatre itself, if needed. This is being followed for last 2.5 years in Indore.

Expert Comments

Dr. Jauhari replied that the facilitating part of the transplant law does not stop anyone to make efforts that should be made for the same, as it is absolutely not right also that the body is cut twice but whether it is possible everywhere, that is an issue. Dr. Koushal added that the problem comes because police don't know the Act and hence issue comes with conducting post mortem.

Dr. Anil Kumar added that actually, there are different arrangements in different states. In Andhra Pradesh, they have been able to implement this and the post mortem doctor has been brought to OT. As you shared, it has been happening in Indore too but it does not happen in Delhi. Most places post-mortem doctors don't come to OT. Here, after sunset post mortem is not done and the doctors do not conduct it. Most places it is like this. It's very difficult to make everyone follow the same thing everywhere.

For this, it's better if you go through Rule no. 6 in Transplantation of Human Organs & Tissues Rules 2014 there is a paragraph written on this. To draft this paragraph we had to conduct 4 meetings with the representatives from different stake holders. Meetings were attended by DCP as a representative of Commissioner of Delhi Police, Heads of the forensic departments of the Hospitals, legal experts and other experts such as Dr. Jauhari. There is highest level of clarity in that paragraph which says that the surgery notes of the surgeon who is retrieving organs during post-mortem are authorized to be considered as part of the post-mortem report anywhere in India. Dr. Anil Kumar pointed that the act says clearly that wherever possible post-mortem should be conducted within OT. Other than that the standard procedure needs to be followed.

Dr. Jauhari also added that the medical report of the retrieved organ should be prepared at the time of retrieval by the retrieving doctors and will be taken on records by the registered medical practitioner doing the post-mortem. This becomes the legal document. The law says that wherever possible, a request should be made to the visiting post-mortem doctor of the hospital even after regular duty timings during organ or tissue retrieval.

Mr. Jeetu Bhagnani from Muskan group Indore added that the Supreme Court has clearly said that medicolegal report or post-mortem report in case of medicolegal cases is a very important document and hence police needs to get it done. Thus, police needs to be involved in the case of organ donation wherever applicable. And this is not mentioned anywhere.

Dr. Jauhari corroborated this by adding that organ donation will happen in the cases where maximum people have met with road traffic accidents and wherever compensation is involved, a post mortem will be conducted for sure. By and large question is one, why did this person die an untimely death? That's all they want to find out.

He read out the paragraph under procedure for donation of organ and tissue in medico-legal cases. He remarked that the law is very clear and the area SHO has to instruct the local police to help in organs retrieval. If they don't, that is



their department issue but the law states clearly everything. The law also says that the determination of the cause of the death should not be jeopardized.

Topic A3

Dr. Koushal wanted to know about when to start talking about organ donation with the family of the probable brain-dead person or how to ensure donation happens in right time? He said that these questions were raised by the medical fraternity too in the scientific session organized by NOTTO recently. When should we start talking, early, after first brain death committee report or maybe when we know that there is a potential donor?

Expert Comments

Dr. Jauhari that initiating a discussion around organ donation with the family of a probable brain dead person can be a tricky part. If you start discussing *after* the certification that you can donate organs, by the time family agrees, by the time recipients come to the hospital, there are chances you will lose the opportunity. The reason you have transplant coordinators going around the hospital looking after probable transplant donors is to buy this time.

You should have signs put up across ICU attendant waiting area so that the family has a chance to look at those posters, sign boards, facts on organ donation so that the topic is not alien to them when discussion happens and they understand what organ donation is if an unfortunate moment comes. Doctors shouldn't be beaten around by the families as they are just doing their duty by talking about organ donation. It's part of their job. The actual discussion on organ donation can begin after first brain death certification. There has been not even a single case where the patient has come back after first brain death certification though the person is declared brain dead only when second certification is done. The time gap in between two certifications gives enough time to doctors and recipients to prepare for organ donation, if the family shows some agreement for the same. Though, there are instances when somethings need to be kept a little flexible on the case to case basis.

Follow Up Points

- For Discussion Point A2 - Dr. Jauhari suggested that to combat the issue of lack of diligent post-mortem process one possible solution can be to get on board a recently retired post-mortem official or head of anatomy department, who can be employed by ROTTO and SOTTO as special visitors in odd hours to conduct post-mortem specifically for this purpose and in such cases whenever needed. He can be kept on contract and doesn't have to be someone working in the hospital. Give him salary for that, whenever he is required he should come for post-mortem. We have been trying continuously but then they talk about the same old Act that they won't do any post-mortem after daytime. Remember, THOTA is a special Act and overrules other Act giving you a legal right to calling someone and get the post-mortem done.

- There is highest level of clarity in the paragraph under Rule no. 6 in Transplantation of Human Organs & Tissues Rules 2014 which states that the surgery notes of the surgeon who is retrieving organs during retrieval are to be considered as part of the post-mortem report anywhere in India. The rules under the THOTA act also clearly state that the post-mortem can be conducted in the operation theatre itself where the organ retrieval is taking place.

- Look at the guidelines being followed in Indore to facilitate post-mortem in case of probable organ donation and if possible, it should be replicated at the national level by passing special orders by the central/state governments so as to make this whole process smooth and donor family friendly.

- Conduct awareness sessions and build healthy relationship with the police department to support organ donation and discuss the rules under the act with them, especially those related to conducting post-mortem in MLC cases where organ donation is to be done.



- For Discussion Point A3 - Appropriate Information material on organ donation should be put up around waiting area near ICU so that families can glance through them while the patient is being treated.

In case of probable brain death, the discussion around organ donation can be initiated after first test reports by the committee so that organ donation is efficient in case family agrees to do the same.

B) Protocol for recognition of NGOs on NOTTO Website, Issues related to NOTTO website and NOTTO Toll Free Helpline Number (1800-11-4770)

Topic B1

NGOs requested that properly registered NGOs should be given an official recognition on NOTTO website by displaying their names and logos on the website under NGO section. It will help in getting due recognition and people will also know about the bona fide NGOs working on organ donation in their area. It will also help in raising funds for their work under CSR, as companies will know that the NGO is recognised by the Govt. This request has been made previously also through a letter to Dr. Vimal Bhandari, former Director, NOTTO, in June, 2018 signed by respective NGOs.

To this, Sunayana added that though ORGAN India is registered already with NOTTO still the name is not displayed on the website and the NGO section is empty. She suggested that it will be great if the names of the already registered NGOs is displayed somewhere on the website as it adds to the authenticity factor of the organization and gives recognition to them from a national government organization which will help in expanding work on organ donation.

Expert Comments

Dr. Agarwal responded that as far as this question is concerned, how many of the present NGOs have registered with NOTTO? How many of you have visited NOTTO website and tried to register? How many of you know what types of registration are there on NOTTO. To this many replied that they could not find any such option on the website. He pointed out that this is the problem with many of us as haven't explored the NOTTO website keenly. If you go on the home page, an option comes to login as new user and register oneself under given five different categories. He outlined the steps to enter basic details asked and register an NGO as an institution. Once an NGO is registered then if you click on the category institutions, all the names should be displayed.

To this, Anil Srivatsa questioned that he would like to know what the various benefits of registering on the portal were. The process of registering is unimportant to me and if it's some legal requirement or with some benefits then only he might be interested to do so. Sunayana added that we want to know because many NGOs want to register themselves.

Dr. Agarwal raised a query that how many NGOs are working on organ donation in our country? If I want to know and want to talk to someone then I won't be able to do so if I don't have your details. The purpose is to connect NOTTO with the NGO and the NGOs amongst themselves and also to let everyone know who all are working on organ donation in India. Even if someone from outside country is looking at it, they should know that such and such NGO is working on it. Much more coordination can be done between NOTTO and the NGOs through this.

Dr. Anil Kumar then shared the process to register as an institution on NOTTO website. NGO will be registered under institution. Dr. Agarwal responded that once the NGO is registered under institution then the name can be shown



wherever it is decided and what all needs to be shown related to NGOs, whether contact numbers should be added or anything else etc. This can be decided in separate official meetings with the stakeholders.

He asked all NGOs to register immediately and then things can be taken up. He accepted that looking at all the problems that have been discussed till now it is evident that there is a gross incoordination and all these things need to be sorted out. Somebody saying that transplant games details are not available on the platform shouldn't be accepted as it is very easy to update the details on the website and should be done in a very organized manner by NOTTO. '

Topic B2

Dr. Kulwant Gaur complained that the toll-free number (1800-11-4770) given on NOTTO website is not working for a long time. And when he once tried to contact it on Saturday, he was informed that we don't entertain queries after 5 pm on Saturday by the executive.

Priyanka added that when it comes to sharing of data with NOTTO the Zublee foundation has been receiving many pledges from people and to upload that on NOTTO website Zublee foundation was registered long time back. But they have not been able to upload it as there is some access issue on the website. She shared that they have been mailing about the said issue to NOTTO which has not been resolved yet.

Anika added to it that repeatedly some issues have been coming up with NOTTO website which also needs to be corrected for NGOs to get donor pledges registered on its portal. A lot of time the website has issues and we keep getting logged out.

Dr. Kulwant Gaur asked that is it possible to share the contact number and names of the NGOs working in the respective states if the helpline gets a query regarding the same for example which NGO is working on organ donation in Jaipur, Kota etc.

Expert Comments

Dr. Gupta replied that the website was facing certain issues for some time and the technical people are looking into it and getting it corrected.

To the request regarding sharing of name and contact numbers of NGOs working in states, Dr. Gupta replied that for this purpose the states need to share the data with NOTTO. He said that he has asked Sunayana to share the name and email addresses of the NGOs working on organ donation and they will write to all the NGOs to register. They will also hold a dialogue with all the NGOs, listen to all the problems and share the issues they have with NGOs and what will be needed from them too.

Follow Up Points

- Contact details of all NGOs working on organ donation known to ORGAN India and who have been attending the Conclave have already been shared with Dr. Sanjay Agarwal on his request. They will be shared once again with NOTTO along with this report.
- Since Conclave, the issue of registration with the Zublee foundation has been resolved and the website has become a little friendly for data sharing.
- As suggested by NOTTO, all NGOs should register on the home page as new users under institutions.
- NOTTO Helplines should be active 24x7. Following the conclave, several NGOs tried dialling the NOTTO helpline and it was found to be out of service on many occasions and working on some occasions. That is the wrong impression going out to people who are trying to call NOTTO. As we now have a common donor card, and the NOTTO Helpline is displayed on the cover of that card, the number needs to be constantly working in a proper manner 24x7.
- All NOTTO operators should have the names, numbers and details of the NGOs in various states in case a caller needs help in the specific region.



C) Challenges and the Way Forward for NGOs, Issues due to non-existence of SOTTOs in various states such as Rajasthan & Odisha

Topic C1

Dr. Kulwant Gaur from Rajasthan shared that they have been facing an issue with brain dead committee in Kota which was formed after a long struggle 4 years ago. There is a 1000 bedded medical college hospital in Kota where brain death committee is present but not working. The Director/MS of the hospital or the nodal officer responsible in Kota doesn't want to work on it. They don't make efforts only to push an organ donation through. In a year, two cases have been missed due to this where families wanted to donate organs but the donor had to be transported to Jaipur because the committee was not functioning in Kota, This led to serious problems with donation being unsuccessful even after all efforts.

It was suggested by Mr. Sandipan Arya added that it would be very effective if NOTTO had a designated official in the states to enable organ donation as and when a complaint is raised about the same. Ideally, NOTTO being the central agency should take some responsibility to question and ask the state authority if it is not taking any action w.r.t organ transplantation program.

Expert Comments

Dr. Agarwal replied that the NOTTO has no power to direct any state authority for this issue. This issue needs to be addressed by the state govt. NOTTO has role in only guiding or making policies and act as SOTTO for NCR. It doesn't have any authority over states. NOTTO can only request the authorities but has no power to take an action against them.

Dr. Jauhari added that under the law SOTTO or NOTTO doesn't have any punitive action or power, all they can do it reinspect a hospital and deregister it if not deemed to be fit for being a transplant centre.

Dr. Anil Kumar added that one thing can be done, since Rajasthan comes under ROTTO Chandigarh and Dr. Vipin Koushal, present at the Conclave, can take up the issue. He can issue a letter requesting the authorities to support organ donation process diligently.

Dr. Koushal replied that the timely and fast creation of SOTTOs is the first step to fixing this issue. At the moment in Rajasthan SOTTO is not playing a role, therefore ROTTO is not in the picture as it will only coordinate with the SOTTOs. To support this point one good example is the case of Rajasthan state where AIIMS Jodhpur is designated SOTTO but Jaipur is coordinating directly with the ministry about their status without taking ROTTO Chandigarh into loop. Therefore, ROTTO cannot coordinate with Kota as there is no structure and clarity attached.

Therefore he said, the ministry needs to expedite the creation and running of the SOTTOs first. Only then ROTTOs can step in and play a role of coordination and active participations as in the case of Kota. The files of UP, Haryana are also pending with the Ministry. So, information should be forwarded to us. At the moment, if someone is doing any activity ROTTO has no information. Thus, making of SOTTOs is very important. Decisions to be taken at the level of health secretaries get delayed by back and forth of forms.



Topic C2

Mr. T. N. Panda brought up the struggle he has had in Odisha with the setting up of SOTTO and enabling a functioning environment for organ donation and transplant program. Following is the issue as quoted by Mr. Panda in the conclave:

"In course of deliberations in the conclave Nov 2016, I pointed out that AIIMS, Bhubaneswar did not have the necessary facilities (They don't have even now) and hence SCB Medical College at Cuttack in Odisha be permitted to house the SOTTO. On getting the verbal consent of Dr. Vimal Bhandari and Dr. Anil Kumar I could persuade the Govt. of Odisha to request the Joint secretary of Health Dept., GOI in Jan. 2017 for approval to start the SOTTO in Odisha, at SCB Medical College Cuttack. Nothing happened till November 2017 conclave, where I again requested Dr. Anil Kumar and accordingly he arranged and sent the necessary forms to Dr. C.R. Kar, the Nodal Officer of Odisha for transplantation.

Subsequently, the Govt. of Odisha sent the forms duly filled in to the Joint Secretary of Health Dept., GOI in the month of April 2018. But instead of conveying the approval after repeated calls, a set of forms have been sent by the concerned section of CGHS, two months back (in September), asking for signing of an MOU between the Govt. of Odisha & the Govt. of India, as if they are not some government but private bodies. However, the MOU has been sent back after being duly filled in. But on November 2, 2018 he received a reply from NOTTO seeking an explanation on why AIIMS Bhubaneswar shouldn't be designated as SOTTO?"

This back and forth between the two government agencies has led to a delay in implementing the organ donation program and has raised following questions -

- Why is there a delay in the process for Odisha? Why can't NOTTO expedite the process?
- AIIMS Bhubaneswar doesn't have the required facilities for transplants; they have appointed a nephrologist just 2 months back only. Can it be a SOTTO?
- After the writ petition filed by Mr. Panda, the Hon'ble High court directed state govt. to adopt the Jeevan Uphaar scheme is a scheme proposed by the state govt. of Odisha to promote cadaver organ donation in their state, something on the lines of Jeevasarthakathe in Karnataka and Mrithasanjeevani in Kerala. The Scheme intends to fund transplants for people in the States. In 4 years after that they have not adopted the scheme, rather sent a proposal in April 2018 only to the central govt. to seek permission to start cadaver transplantation in Odisha.
- Mr. Panda added that he had detailed discussions with Dr. Anil Kumar, Dr. Manas Pratim Roy of CGHS and Director NOTTO in the 1st week of Nov. 2018. All of them are of the opinion that since the Odisha legislative assembly has already adopted the central act, it becomes the State Act, and therefore central govt. permission is not necessary. He requested that the letter should go immediately from central govt. saying that the permission is not required and that they can decide themselves regarding organ transplantation.

Expert Comments

Dr. Anil Kumar replied that the letters have gone to state health secretaries from joint secretary to set up SOTTOs, and while some states have replied and some have not. He shared that 3 SOTTOs have been sanctioned recently viz. Rajasthan, Madhya Pradesh and Kerala. More proposals are pending and are under process as the ministry is promoting setting up of SOTTOs in the states where the transplant act is already adopted. Only 14 states have adopted the act till now.



One cannot expect everything from the centre to speed up the process. The state government has to take up the responsibility, and the funding of SOTTO can be only through state govt. Also regarding monitoring, Central govt. is also facing issues in struggling with states to ensure networking and sharing of data as many states are resisting it. Deceased organ donation is not being promoted in many states. Efforts need to be put to do it and one has to understand that centrally we don't have adequate number of staff to monitor each and everything in detail. Central govt. has to make policies also, make amendments, fight court cases wherever Govt. of India is a party.

Dr. Anil Kumar said that in case of Odisha, the proposal is definitely under process and it will happen. But he wanted to highlight that having a SOTTO in the state is not paramount. States can themselves decide about organ transplant matters; wherever SOTTO is not there the State Health secretary can decide regarding organ allocation and other processes.

He shared an example from a transplant centre in Silvassa in Union Territory of Dadra and Nagar Haveli, which was recognized as a retrieval centre. Since getting the recognition they have not been able to do even a single organ donation in their facility and now are requesting to set up a SOTTO. So, SOTTO shouldn't be set up only to get funds from centre. One needs to first show work in their area as there has to be some utilization pattern. Dr. Badhan added that Indore has done good work without having a SOTTO and all the other states should learn from their example.

Regarding Jeevan Uphaar Scheme in Odisha, Dr. Anil Kumar shared that the proposal letter has been received by MoHFW from Odisha Government to implement 'Jeevan Uphaar' scheme. However, in their letter, they have not mentioned that they have not recognized any hospital to conduct cadaver transplantation. This fact has been highlighted by Mr. Panda in this session. The state govt. had shared the scheme, but nowhere they have mentioned that they are not permitting deceased donor transplants, which is definitely legally challengeable that why they are not allowing it and why they actually need separate permission for that.

Dr. Jauhari noted that the struggle in Odisha has been going for long by Mr. Panda and somehow the state govt. and the central govt. have other priorities. He suggested that Mr. Panda can approach the high court with a writ petition saying this is an urgent matter and some answers are required from the State Govt. and the other Govt. People are dying and he as an NGO has all the right to go to court and get it addressed. He will get an answer facilitated by the court straightaway. The Court will accept the petition and if the directions of the court are not followed, it will be a contempt of court.

Follow Up Points

- Dr. Anil Kumar said that there is some sort of misunderstanding in the minds of the people managing organ transplantation in Odisha state, and requested Mr. Panda to share the contact details of the concerned officials so that he can have a discussion with them about the same and get it solved. Dr. Agarwal also assured Mr. Panda that he will take it up and follow up on this.

- Ministry needs to expedite the creation and running of the SOTTOs first on an urgent basis and ROTTOs should be in the loop and actively involved in coordination and participation. This way incidents such as the one in Kota can be dealt with efficiently. Existing SOTTOs need to be in close touch with ROTTOs. Nobody in State should be coordinating directly with NOTTO, especially when they have fully functioning ROTTOs. The files of UP, Haryana are also pending with the Ministry. Information should be forwarded to ROTTOs so that they can actively participate in creation of SOTTOs.

- On being requested, Dr. Promila Gupta noted all the points taken up in the discussion and assured to act on them as soon as possible. She said that a meeting with all the state health secretaries is scheduled to take place soon, and the matters highlighted in the conclave will be discussed. Until we involve the highest authority, these things will not be addressed at the core. We will definitely do this, but the states also have to do their share as it is a two way process.



D) Guidelines from NOTTO for the use of NOTTO logo and name on certificates, IEC material during collaborative events, Use of logo on non-collaborative events, Use of 'Under the Aegis of NOTTO', Guidelines for conducting training sessions for transplant coordinators by NGOs

Topic D1

NGOs raised a concern that in case of collaborative efforts of the NGO and the NOTTO to conduct an awareness event in their region, adequate status should be awarded to the NGOs efforts and requested a set of guidelines be issued for use of logo on certificates, IEC Material etc. for events to ensure smooth coordination at both ends.

Some NGOs faced a lot of issues in coordinating and getting approval for the placement of NOTTO logo on the collaterals for the event which led to back and forth of design draft of the material a number of times, leading to discomfort on both sides. Ms. Pallavi Kumar from MOHAN foundation shared the issues they faced while coordinating a certificate design for one of their trainings which led to some tension and unpleasantness.

Anika Parashar said that all of us would like to think that we are limbs of NOTTO. She added that there are many events ORGAN India does with NOTTO and surely other organizations do too. Though the work is acknowledged, there are definitely different rules that apply for different events which are not specified in any guidelines. We do see ourselves as the extensions of NOTTO and it would be good to have clarity in such matters.

An official communication with the appropriate guidelines in this matter will save lot of efforts and time for both the NGOs and the NOTTO resulting in quick approval and smooth collaboration between the two.

Expert Comments

Dr. Jauhari said that as NOTTO is an apex Govt. body, therefore there has to be a logo design which needs to be placed appropriately and cannot be put in the midst of other logos. There will be objections if anything is found incorrect. There will be instances when the design will be sent back to the NGO by the NOTTO for further editions and revisions, but this all is part of the government protocol to be followed.

Topic D2

Ms. Pallavi Kumar shared that the MOHAN foundation has been conducting trainings for the Transplant Coordinators for last 10 years or so and this year alone they have trained 336 Transplant Coordinators along with NOTTO. With the setting up of NOTTO they had thought that the things will be streamlined, on the contrary the things have gone awry. She asked if at all MOHAN Foundation has been adding value to the program and added that they have not been given any official training partner status.

MOHAN is questioned about why they are charging a training fee. They have to take care of travel, accommodation and other logistics for NOTTO Team, which leads to an added cost. If there is any issue with the Foundation giving training it should be discussed by the NOTTO and they should clarify their stand on it.

Anika asserted that MOHAN foundation is the best at training and have mastered it, and like them, each one of us NGOs have our own strengths. The idea of coming together is all about taking all strengths together and making one collaborative effort. So, while the government may not need any NGO for any purpose, the question is if MOHAN is doing it then why not let them do it for you?



Expert Comments

Dr. Promila Gupta added that in the current scenario the main point of contention could have been that NOTTO doesn't want MOHAN foundation to charge fee for the training, which they do currently, especially for the Govt. Transplant Coordinators where NOTTO will not like them to charge anything.

To this Pallavi requested that in order to ensure this setup works there should be then some form of financial support provided by NOTTO, as the training definitely has a cost attached to it which includes venue, food and delegate kits etc. provided by the NGO. To this Dr. Gupta replied that she thinks that can be discussed and taken care of, and not just for MOHAN foundation but for any other organization as well which is interested and is capable enough to provide training. NOTTO/Ministry can conduct a dialogue with all the training institutions both government such as AIIMS, Safdarjung and non-government organizations. So, there can be few representatives from NGOs, few from Govt. institutes and then all the raised issues can be deliberated upon. But on the certificate they would like to have only NOTTO stamp or a bigger in size NOTTO stamp and on sides it can be for other organizations as it brings more value addition to the certificate.

Dr. Promila Gupta added that they will invite all the NGOs interested in training or are imparting training. They will listen to their views and workout a program which is practically possible, and see if financial support that can be provided. We will all work collaboratively on this.

Dr. Agarwal replied that saying NOTTO doesn't need NGOs is wrong. NOTTO needs everybody who is contributing to the cause. He added that each NGO should specify what they need and then action will be taken accordingly.

Dr. Jauhari said that one should not doubt the intentions of the NOTTO, as it is always there for anyone as an umbrella body. Now, whether MOHAN does training, ORGAN India does anything or Dadhichi does body donation; it may be 99% their work but 100% will always be NOTTO. Extra 1% will always be reserved for NOTTO. Therefore, being a Govt. body we have had collaborative training programs suggested by MOHAN and should be carried forward in future too in the form of a one day training, one month course, a year-long course or others.

Topic D3

NGOs raised queries regarding the use of 'Under the aegis of NOTTO' in the collaterals and awareness materials, to those NGOs who have been given a permission to conduct activities under the aegis of NOTTO. The concern was where all can the above phrase be used and if we need separate permission every time someone uses it whether on IEC material, donor cards, event collaterals etc. Also clarification is needed on how and when the NOTTO Logo can be used by NGOs who are Under The Aegis of NOTTO.

Ms. Priyanka from Zublee foundation wanted to ask a question concerning her organization. The term 'Under the aegis of NOTTO' supports and protects us when we are doing anything in collaboration. She mentioned that Zublee foundation did an event 'Organathon' which was a term coined by them. In 2017, the second edition of the event was conducted in collaboration with NOTTO and we had Dr. Bhandari and Dr. Badhan graced the occasion. This year, in 2018, NOTTO organized this run 'Organathon' and Zublee foundation was not informed by NOTTO.

Priyanka added that they do not want to lose the originality of the name as people will get confused that whose event it is. They have filed a copyright regarding the name which is in the process.

Mr. Sandipan Arya asked that for those NGOs already 'Under the aegis of NOTTO' can we use the logo of NOTTO on the awareness activity banners and informative material without asking for permission for each one.



Expert Comments

Dr. Jauhari shared that for the activities other than collaboration between an NGO and NOTTO, we came up with an idea that it can be done by using the term, 'Under the aegis of NOTTO'. NGOs can do this as long as one doesn't do something outrageous or illegal. NGOs should also send NOTTO, ROTTO and SOTTOs a list of activities that they have conducted Under the Aegis of NOTTO.

Dr. Jauhari that as far using the Logo is concerned, as said that foremost NGOs should tell their intention for the same and what they want to do. He added that NGO should inform NOTTO what they want to do, take permission to add logo, show the sample copy to NOTTO, get it approved and then use it, if allowed. These things have to be followed under the strict instructions.

Dr. Agarwal added that anyone's logo cannot be used by anyone else without written permission. This is general rule regarding the logos. Dr. Gupta also confirmed that one cannot use the Logo without prior permission.

Mr. Arya said that this is what we all are requesting you to set up a system so that the communication between NGOs and NOTTO is prompt. Mr. Kulwant requested if we can get a letter stating where all the NOTTO logo can be used.

Dr. Gupta added that first and foremost all NGOs need to be registered on Darpan portal of Niti Aayog for them to interact with Govt. of India. That is one of the foremost requirements and latest condition for the past one year.

Follow Up Points

- The main issue which is that there are no fixed guidelines set up by NOTTO with respect to use of the NOTTO logo. NOTTO is requested to issue guidelines for when, where and how NOTTO logo can be used by NGOs for different activities such as collaborative events, trainings, non-collaborative events under the aegis of NOTTO etc. Each activity may have a different guideline so clarity will help reduce the work involved.

Absence of such guidelines leads to confusion, delay on some occasions may lead to unnecessary unpleasantness on both sides. Therefore, it would be best if guidelines can be framed and shared with all NGOs as soon as possible.

- All NGOs should register on Darpan Portal of Niti Ayog to further interact with NOTTO according to the rules of engagement laid by the government.

- Any NGO who wants to issue donor cards on behalf of NOTTO should get the soft copy from NOTTO and send their card for approval before issuing it.

- The term Under the Aegis of NOTTO can be used by those NGOs authorized to do so. However, they have to be careful how they use it and not do anything illegal or outrageous. All NGOs need to share monthly or quarterly reports with NOTTO on their activities so that NOTTO is aware of the work being done.

They should also share these reports with their respective SOTTOs and ROTTOs. This will help in keeping everyone abreast about activities and will help in further collaboration.



E) Organ Donation After Cardiac Death

The issue was briefly brought up during the conclave by Mr. Kamal Khurana from Dadhichi Deh Dan Samiti to know more about what is organ Donation after Cardiac Death (DCD), whether Donation after Cardiac Death was being actively promoted by the government, and if it was alright to do so. Mr. Khurana added that since deceased organ donation after brain death is less it might be beneficial if the govt. also promotes donation after cardiac death.

Dr. Jauhari replied that donation after cardiac death is fully permitted and the law is very clear and the definition is very clear in the rule book on Page 2 under section 2. He added that promoting donation after cardiac death in current scenario will not be an intelligent option as even for organ donation after brain death, the infrastructure is not adequate, surgeons are not there, trained nursing staff is less, and trained transplant coordinators are less. One needs to understand that if we are making a national policy it has to be reproducible. It has to be properly planned and then the technical things should be left for the professionals.

F) Data Sharing between States and NOTTO

Dr. Vasanthi Ramesh said that last year, according to whatever data NOTTO had, our country had around 900 donors. This year in 2018, we have 892 kidneys have been donated through deceased organ donation, 459 livers have been donated, lungs and heart donations are 180 and 145, respectively. These are exact numbers and verifiable. These numbers are surely not the entire country numbers as the data is under reported or not reported by all organisations in all the states of the country. Thus, country statistics are shown less overall and a grim picture of organ donation rate in India is reflected globally.

Dr. Jauhari said that under the laid law we all have to do what work we have been asked to do. NOTTO has been requesting everyone to share their regional and state data but the people are hesitant to join the national program. Failing to understand the reason behind this hesitation, he added that India is much better in terms of organ donation but only if the correct data is projected cumulatively. Unless we all come together and give data to ROTTO, SOTTO, and NOTTO the things will not show on the national and global platform.

Mr. C. E. Karunakaran from NNOS foundation in Tamil Nadu highlighted the fact that Health is a state subject and so far the states which have been actively doing work on organ donation have themselves pushed the program. They are doing this program differently in their own region and NOTTO should play the role of a facilitating body to help the remaining states to set up a proper organ donation and transplant program.

Dr. Gupta replied that already NOTTO is ensuring decentralization of the program and the states are running it. NOTTO in no way is controlling or stopping the states from implementing their own program. Dr. Jauhari added that the states also need to share data with centre. Why it is not being done? The hospitals are not sharing data with NOTTO and there is a certain lack of transparency over the same.

Mr. Karunakaran agreed to it that the data should be shared by the hospitals to their SOTTOs and then the states should share data with ROTTOs and then the data should reach NOTTO.

Dr. Jauhari added that NOTTO has every right to ask for the data and the data should be entered properly on the central registry.

Dr. Agarwal added that he fails to understand the logic behind what Mr. Karunakaran is saying that they will share the data with SOTTO whereas all a hospital has to do is share the data with the central agency and all SOTTOs, ROTTOs and NOTTO will have access to it. So, it's better to enter in the central system. He added that the data sent by Indore is on paper. If the same data is shared online it will be better and more accessible in a single registry.



To this, Mr. Karunakaran replied that how can a single registry suit every state when it comes to the distribution of organs. What if a state needs to have a different MELD score before liver transplant and others do not want to adopt it.

To this, Dr. Agarwal interjected and shared that each state was directed to locate their guidelines. You tell us what guidelines you want to and that will be included in NOTTO guidelines. NOTTO is only an advisory and states are allowed to follow their own guidelines. But no state told NOTTO that they are following certain guidelines so that the same can be updated and made available for Tamil Nadu.

Mr. Karunakaran added that there are 2 types of registry – one is waitlist registry and the other is post-transplant data registry. The Act and the Rules are very clear that it is the post-transplant registry that is mentioned for sharing, and not the waitlist registry.

To this, Dr. Jauhari objected and raised 2 points. Firstly, if there is a patient registered on the waiting list with Delhi and with Tamil Nadu, without sharing of data NOTTO will not come to know if the same patient is registered on multiple platforms. NOTTO must know as the patient is not allowed to do so. Let him choose one hospital and stay there while waiting for organs.

Secondly, you are saying that each state has its own criteria. Now, you are contradicting yourself by saying that the two adjacent states might have different allocation criteria. In such case, if state A accepts organs till 70 years of age and state B accepts organs till 60 year of age then should state B send organs of above 60 years to state A and they should start getting the organs. We are still one country and one country will have to have common guidelines. And all states need to follow it.

Dr. Agarwal added that all that is being asked from you is to share the allocation criteria guidelines which are more or less going to be similar to others as the process of transplant is same whether in Andhra Pradesh, Tamil Nadu or Delhi. It is only 10% which will vary and that 10% can also be added to the central guidelines so that you can select out of it whatever you want. NOTTO will never force you to follow its allocation criteria. What is the problem in sharing state's waitlist registry and following your own allocation criteria and why can't you inform all of us about what you are doing?

G) Transplant Games for the Donors and Recipients

Anil Srivatsa from Gift of life Adventure shared his personal experience and struggle to reach out to the concerned officials to register and participate in the World Transplant Games. He pointed to the fact that Sunayana brought up discussion on world transplant games. He spoke about how people in North Indian states are not being able to participate as much as people from South Indian states are such as Tamil Nadu, Bangalore (Karnataka) etc.

He shared that he has been trying to participate in those games for last 3 years and could not find anybody who could respond and let him know how he can do it. He pointed out that he did some research himself, found the contact number of Dr. Aulakh who is the contact person for the same but did not have contact details displayed on the world transplant games website. He did research himself and tried to contact Dr. Aulakh but he had no time to respond to his messages. Again, he was caught up in the politics of the system. As far as an understanding goes, transplant games are an incentive to the donors and the recipients to showcase their life after transplant and inspire others through their journey.

Dr. Agarwal responded that the best thing to do will be to contact the secretary of the Indian Society of Organ Transplantation. They will have all the access and numbers of the person to be contacted for this.

Due to the lack of a definite answer during the discussion, Sunayana suggested that this should be noted down and we should get the list of the contact persons and organizations participating or taking care of the transplant games, and then share with everyone post conclave. This information should be shared with others also whoever is interested to participate.



THIRD COLLABORATIVE CONCLAVE for Organ Donation



Dr. Jauhari added that Dr. Bharat Shah is the person doing the transplant games and there are few other organizations doing it. But the question is very valid that whom one should speak to regarding transplant games.

Sunayana also suggested that she can share the contact details of Reena Raju with Anil Srivatsa and he can ask her to share further details about how to proceed with participation in the games. We should involve more NGOs and organize transplant games or something like that for northern region also where donors and recipients can come together and participate.

At the end of the discussion session, Anika added that there is a possibility that during the discussion we might not have had all the answers but that is the reason we all have gathered here, to deliberate upon issues as one collective forum.

Follow Up Point

For 2019 World Transplant Games, Ms Reena Raju from Reena Raju Light a Life Foundation is the team manager - India. This year the Reena Raju Light a Life Foundation has got India's membership renewed with the World Transplant Games Federation. The Foundation has been actively involved for the preparations of the world transplant games and anyone interested to participate in the games should register with them or contact Reena Raju on the following email Id - reenalightlife@gmail.com or mobile - +91 9739099296.





Session 4: How NGOs can partner with Hospitals to encourage and setup an Organ Donation awareness program

Speaker



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

Ms. Pallavi Kumar took a session on implementing a deceased organ donation program in partnership between NGOs working on promoting organ donation and the transplant hospitals. She suggested that before starting a partnership with a hospital, it is important for an NGO to assess their own readiness and that of the hospital; assess the partnership modalities with the

hospital as some hospitals do not really have a full fledged transplant program. Some hospitals would like to have a partnership where a full time coordinator is based at their premises and whenever a deceased organ donation is about to happen, the NGO is informed to facilitate coordination and counselling of the stakeholders. Along with this, a dedicated transplant coordinator conducts awareness initiatives at the hospital, is involved in the counselling of the possible donor family, and thus supports the transplant program in totality.

As an NGO, one has to look at the financials and should do an agreement with the hospital about the same. For example, MOHAN foundation follows a partnership model of 80-20 with some hospitals in Delhi-NCR where the coordinator is a permanent employee of foundation and is paid salary at 80-20 ratio by the hospital and the foundation, respectively. Monitoring of the activities of the coordinator is sole responsibility of the foundation.

She stressed upon the fact that there has to be one person as the champion or convener of the program in the hospital and a formal MOU to make it more effective. The top management should always be on board and there has to be a formal policy for deceased organ donation and transplant in the hospital. There has to be a transplant committee with all major stakeholders, involved in the transplant program, as members of the committee.

Other important things include separate deceased and living organ donation coordinators, proper counselling room, defined SOPs for the whole process, proper forms to be filled during the actual donation, designated brain death committee, set protocol to be followed at the hospital in case of organ donation, set protocol for sharing of organs with other hospitals, designated funds for awareness activities, funds to build supportive facilities for donor family, arrangement for transportation after organ donation, data management and documentation, ongoing training and sensitization of hospital staff, building healthy relationship with local police, forensic team and others.

She insisted that the designated transplant coordinator should be visible as a part of the treating team and not an outsider who appears only to convince family to donate organs. The coordinator should be projected as a social worker and should meet the family every day, sharing regular updates on patient. The coordinator should sensitize the family and speak about organ donation to let the family know about the possibilities, only after first brainstem death tests are done and confirmed.

Discussion Point 1

Mr. Sandipan Arya asked Pallavi that according to her when is the correct time to discuss organ donation with the family of a probable brain dead patient. As officially the brain death is declared only after second confirmation test is done but for practical purposes it might be too late to discuss in some cases.



Expert Comments

Pallavi replied that it's a little difficult if you are an external party to the whole setup. Thus the best model is that a transplant coordinator should be present and seen as part of the treating team, as a social worker who meet the family every day, shares updates with them regularly and build trust with the family. The discussion on organ donation should begin only after first brain death certification process. If you strictly go by rules the person is declared dead only after second certification is done. But for all practical purposes the conversation should begin after first brain death certification only.

Dr. Badhan added that the sensitization of the family can begin after first test and the possibilities can be discussed after first declaration.

Mr. Arya shared that in one of the cases in a private hospital, the first brain death certification was done and the patient was shifted to a govt. hospital. There was some miscommunication among doctors and the media was called before second brain death declaration. If practically we can start talking to the family after first declaration then why not include such provisions in the law itself.

Dr. Agarwal replied that by law, one cannot speak to family for donation after first set of tests are done. Also, direct conversation has not proved an active role in organ donation. A discussion of possibilities and sensitization of family members is important instead of directly talking to family about a donation.

He also said this can cause complications, For example in a hospital a transplant surgeon started going to neurosurgery ICU to identify the potential donors in the neurosurgery department. After which the whole department got furious and never cooperated in declaring any single patient for next 10 years. Minor incidents like this can affect the whole process in a long run.

Dr. Agarwal added that the alert that goes out via whatsapp or email is only for few hospitals in the state and for SOTTO about a potential deceased organ donor but no action should be taken on the basis of that. If some hospital starts calling people (the media, the recipient families etc.) only on the basis of that alert then it is completely wrong on their part. They are not supposed to do that and it was wrong if it took place and the person should be reprimanded if it happens.

Discussion Point 2

A question was raised as to why there should be 2 different coordinators for live and deceased organ donation. One person should be able to do both. A question was raised by Dr. Agarwal about who is training these coordinators who work for live organ donation and transplant as most trainings currently are focused on deceased organ donation and not organ specific. He also added that the Govt. hospital doesn't differentiate between transplant coordinators for living or cadaver organ donation. Dr. Gupta added that if the hospitals are dedicating human resources for specific organ transplants then who is training them and what is the part of their training.

Expert Comments

To this, Pallavi replied that the coordinator facilitated by MOHAN foundation to hospitals is only for deceased organ donation whereas the hospital has a coordinator for live organ donation separately. She thinks that there should be different coordinators because the counsellor should not interact with both donor and recipient families. Most of the private hospitals have separate transplant coordinators for every transplant unit and for live and deceased organ donation. She said that almost 75% of the training curriculum is similar for both and the rest 25% consists of counselling, role play which is specific to deceased organ donation.



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Dr. Koushal added that for even at PGI Chandigarh they have different coordinators for live and cadaver donation as the task is huge in living donation also and they have lots to work and coordinate. He added that the minimum qualification of the transplant coordinator is any graduation, nursing etc. and hands on training is given and a transplant coordinator is a coordinator equipped with all knowledge. It's just that they have been assigned certain roles and responsibilities in case of living organ donation or deceased organ donation.

Mr. Santosh Andhale added that why not chalk out a common syllabus for transplant coordinator training and give it to everyone.

Dr. Badhan added that NOTTO does have a standardized curriculum for training. The basis for the module was MOHAN foundation course but now NOTTO has added certain things to the module and everyone has been directed to train the coordinators using the updated curriculum.





Session 5: SWAP Donation and Transplantation – How to be more effective

Speaker



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

Dr. Ganesh Sanap, Clinical Operation Head, Apex Kidney foundation, spoke about allocation and matching in a kidney exchange program. He explained the process of swap transplants and spoke about the APEX swap transplant registry which has been developed and maintained for years now to facilitate kidney swap transplant. He shared that currently they are in the process of developing an application, along with IIT Bombay, to list and match donor and recipient in a renal swap transplant in order to reduce the waiting list and find a good match for the patients efficiently.

The program is based on 3 basic principles of cardinality, equity and utility. The rule is to figure out how more and more patients can benefit with the program matrix ensuring fairness to all the transplant patients and equity along with the maximum utility of the available kidney.

The gap between the demand and supply can be closed through living transplants, cadaveric transplants and the paired exchange where the patients and the donors who come together, are paired and matched to each other. Then, he demonstrated the use of the application with an example and showed that how it displays the data related to kidney paired exchange program. He said that with a robust swap transplant registry, built with data shared with the help of everyone's cooperation across, we can increase the overall number of kidney transplants.

He shared that a scoring system has been set up keeping in mind the cases which need urgent attention. If there are sensitized patients they get higher score and an unbiased system is put up keeping in mind all the scoring and the nephrologist recommendations.

He shared that, right now, whatever swap transplants are happening in India they are at the level when the dialysis patients in the dialysis center itself discuss among themselves and decide to go for a swap transplant, in consultation with their treating nephrologist. These are happening at the local level. If there is a state based registry then a suitable match can be found for a difficult to match patient, as all the hospitals and patients will be registered on the state list. This could give new lease of life to many.

Discussion Point 1

Sunayana asked Dr. Sanap what they do if they get any calls with request for swap transplants from Delhi or other parts of India?

Expert Comments

Dr. Sanap said that they do get calls from patients from Delhi. There are many registered in the database. Recently, one binary swap transplant was conducted at Miranda Hospital. They try to match patients from the same cities and these two families from Delhi were matched and transplant conducted. They try to match best suitable patients and try to find a match from same region keeping in mind the logistics involved.



Discussion Point 2

Dr. Sheetal Joshi asked Dr. Sanap, if there is a system of scoring in case of patients needing transplant on an urgent basis when registered in swap transplant registry.

Expert Comments

Dr. Sanap replied that there is a system set up keeping in mind urgent cases. If there are sensitized patients they get higher score and an unbiased system is put up keeping in mind all the scoring and the nephrologist recommendation.

Follow Up Points

- There is a need of a combined swap transplant registry both at the state level and national level. All states need to set up a swap transplant registry.
- There is a need for the official guidelines stating which hospital the swap transplant can take place in as that becomes an issue.
- There is a need to draft guidelines for getting NOCs from the authorization committee at the hospital level to make swap transplants easier and quicker.





Session 6: Role of NGOs in promoting Body donation

Speaker



Mr. Harsh Malhotra, President, Dadhichi Deh Dan Samiti

Mr. Harsh Malhotra began with paying his tribute to Late Mrs. Kirti Parashar and thanked ORGAN India to organize the conclave every year diligently and in a bigger way the following year. He emphasized that the conclave has proved to be a very useful platform for the cause of organ and body donation. Dadhichi Deh Dan Samiti has been working for the promotion of this cause for the last 20 years in the region of Delhi NCR. Till date, more than 10,000 people have pledged organs and body donation with the

organisation. More than 225 body donations have been coordinated by the organisation in the medical colleges of Delhi. More than 600 pairs of eye donation have been coordinated and 4 deceased organ donations coordinated.

He highlighted the work of the organisation, their success stories and the efforts put in by the organisation and its volunteers to raise awareness around body donation and organ donation. He spoke about the role of all NGOs in promoting body donation across the country.

In order to overcome the religious barrier faced in the cause of organ donation Dadhichi Deh Dan Samiti organizes utsavs and involves a religious leader in the same to pass on the message of body donation. This is a major barrier and we need to address it in order to promote organ and body donation. He said they keep talking to people in all religions and different groups.

Along with Delhi NCR, the organisation also tries to coordinate body donation in the areas around Delhi such as Mathura, Lucknow etc. They guide the person who contacts the organisation and facilitate body donation.

The organisation is now collating the data to display the contact details of all the organisations, both government and non-government working for the cause of organ and body donation on their website in an effort to make it available for all.

Discussion Point 1

Mr. Sandipan Arya shared that the six medical colleges present in Indore have a good number of cadavers donated for the medical research and thus, the cadavers are being sent to other medical colleges outside Indore and all over India. This is being facilitated by the government itself which is a huge step in promoting body donation.

Discussion Point 2

Ms. Sunayana Singh updated all the participants that even ORGAN India has an online Body Donation Directory which can be accessed on <http://www.organindia.org/overviews/body-donation-directory/>. Anyone may refer to the directory if they need to help in facilitating body donation in their state.

Session 7: School awareness program by A Million Pledges

Speaker



Mr. Jesal Mehta, Founder Member, A Million Pledges

Mr. Jesal Mehta, Founder Member, A Million Pledges, presented the work of the organization and shared their success story. He discussed that in last 2 years after they started working to promote organ donation, the organisation realised that younger the audience more receptive they are to the message of organ donation. Older audiences generally carry a number of myths and dogmas along with them.

He discussed the school program which is being developed by them in order to sensitize school children, their teachers and parents about organ

donation. They are planning to spread the message among children and thus bank upon their persuasive power to talk to their parents and other adults in the family to promote and pledge for organ donation.

They started with their Alma Mater school and spoke to students of age group 8-14 years. They got an overwhelming response from the students who participated enthusiastically in the discussion and put up good questions about organ donation.

Thought the conversion rate will show up only in few years down the line owing to the target age group but it is imperative that the discussion around organ donation begins among school children now.

Currently, they have been discussing about organ donation with all the schools across the country under the Don bosco group of institutions, where they come from personally. They have taken on board the principals to allow the organisation to speak to their students and conduct presentation for them on organ donation awareness.

The program is still in initial stages and everything is being planned including the agencies, logistics and collateral etc. involved to spread the message across all the concerned schools in the country.





Session 8: Raising awareness on organ donation - What to focus on

Speaker



Mr. Anil Srivatsa, Managing Trustee, Gift of Life Adventure

Mr. Anil Srivatsa shared his emotional journey as an organ donor and how he makes all efforts to encourage people to pledge organ donation and start the conversation with their family about organ donation. He has travelled all over the world in his own caravan and has spoken to many schools, colleges, organization, people on the way near highways who receive less attention otherwise because they are not in the mainstream.

He was of an opinion that organ donation is an act of love, both at macro level and micro level. Generosity that is displayed at the time of organ donation is more in Bharat. Organ donation is all about love and there is more love in Bharat (rural India) than in India (urban India).

He said that he has spoken to around 30,000 people till date about organ donation and he talks about his own journey as a kidney donor. He tries to encourage people by sharing his own experiences and path he has travelled being an organ donor. Whenever he conducts a session and people ask where they can sign up, he asks them to start the conversation at home first instead of just getting a card after sign up as that is the only way to get it done for sure. But as for some organizations the only way of showing tangible results is to keep a count on pledges, so they should send certificates to those who pledge so that they can display it and it's visible to all family members. There needs to be more involvement of recipients in the process too.

Organ donation stands on the three pillars viz. social pillar, medical pillar and the legal pillar. He deals with the social and legal pillar. He keeps trying his best to get some positive changes in this matter. He shared that if influential leaders in the society can get kidney transplant as early and comfortably as possible, which means it can be done, then it should be possible for common man too. He has filed many writ petitions in different courts on these matters, one of which he had won. He said that people should be more aware of their legal options.





Session 9: Role of Crowdfunding in Organ Donation – How to raise funds

Speaker



Mr. Anoj Viswanathan, Co-Founder & President, Milaap

Mr. Anoj Viswanathan took a session on the role of the crowdfunding platform in funding medical treatments. It is a platform where anybody can come, put up an authentic need, and get it funded through small contributions by people from India and all over the world. It is essentially fundraising primarily aimed for individuals contributing to individuals per se. They started in 2010 and specifically started to focus on medical treatment needs in 2014. Some of the cases or causes that get funded are transplants, cancer treatments, NICU, PICU etc.

People are raising money for friends, colleagues, and family members. They have been able to raise INR 450 crores for the various projects till date. Nearly 70% has come from India and more so from tier 2 or tier 3 cities. Specifically medical needs constitute more than 60% of all funds raised esp. for tertiary care needs. Over INR 250 crores was raised for 15000+ patients.

He said that the platform does not discriminate between people on the basis of their social or financial background as far as the need is authentic. The research data shows that 40% of all pediatric liver transplants conducted last year were crowdfunded on Milaap. He shared some case studies and stories from their platform where the family was helped by funds raised through crowdfunding on the platform.

As an approach to medical fundraisers, they have built network with hospitals involved in tertiary care where they sensitize doctors and coordinators about it. A level of sensitization is needed to make people feel comfortable about fundraising. There is a process of authentication and identification of the patients or beneficiaries recommended by doctors etc. Fundraising page is launched within short time for the beneficiary. They transfer raised funds to designated account of the hospital or its affiliates such as foundation arm etc. They share an update with the donors periodically, during and post the campaign in coordination with the patient family and the doctor. Internal audit is carried out in terms of bills and invoices that are raised by the beneficiaries or the hospitals.

Firstly, the patient has to approach Milaap to setup a page for them. The process of page setup is well defined, beginning with supporting letters and documents provided by the doctors (in most cases). Page can be setup in vernacular languages also. Verification of the story is done and the person is asked to promote the page within their network first to give it a start and more visibility.

Later, social media outreach is another way of reaching out to donors through multiple social media platforms of Milaap. Once the campaign is live with initial contributions, they share it on their social media channels and blogs. Together, they reach over 10 million people every week for various needs. They curate stories for the beneficiaries who are in an urgent need of funds and promote the same on their social media. They do push stories that require urgent attention. Nearly 40% of funds raised is because of the efforts of Milaap in amplifying these stories.

Milaap has strong donor management. They maintain transparency in the process and do have repeated donors. They keep communication, both good and bad news, with their donors systematic and updated. There have been cases when they had to return the money to their donors as the patient's family chose to decline treatment only. It's this transparency and accountability that has helped them gain confidence of their donors as well as people needing help. He shared that they work with all sets of hospitals viz. government, private or charitable hospitals. The challenge is that how well is the hospital or the departments receptive of the idea per se. In the past, they have seen that there is a certain challenge in working with government hospitals, not because of the lack of interest but because of the certain



legalities and paper work involved that has to be done. For example, they have worked with KEM hospital, Tata Memorial hospital etc. in past but generally the hospitals have to be receptive of the idea and the process.

Milaap charges 5% of the funds raised. Setting up of the page is free of cost. They don't guarantee any amount to be raised. Whatever is raised they keep net 5% of the amount and the remaining is transferred essentially to the beneficiary account. What they essentially do is provide a virtual account to the beneficiary. For each of these campaigns, they create a sort of virtual account. Their banking partner is Yes bank. They create a sort of escrow account so it is not going in any common pool but to the beneficiary. The account is essentially managed between Milaap and the campaign beneficiary.

Funds are transferred against the bills and invoices raised and sometimes transferred to the hospitals directly or in some cases given as reimbursements. The supporting bills and invoices are sought in each case.

Session 10: Promoting Organ Donation

Speaker



Dr. Mangala Kohli, Director, Professor and Head, Dept. of Anatomy, VMMC & SJH

Dr. Mangala Kohli shared her experience about promoting the organ transplant program by creating awareness on the ways to live a healthy lifestyle in order to lead to a better quality of life with healthy organs.

She has been organizing awareness sessions through her program 'Dialogue with Organs' designed to make public aware of the difference between healthy and diseased organs through exhibition of real specimens of healthy and unhealthy human organs.

She creates awareness among youth through her adolescent awareness program telling them about healthy organs, healthy lifestyle, normal and abnormal organs. She tries to promote healthy lifestyle in order to prevent diseases. She shared about the various initiatives that her department and she herself has been taking in order to promote organ donation in their own ways.





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