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Editorial Desk

Deceased donor transplants in India during the last decade

The data from Global Observatory on deceased donation during the last decade from India shows that after 2016 the deceased donation rate has plateaued or fallen and not surprisingly last year during the COVID-19 pandemic it was less than half.



Deceased donor transplants in India from 2013 to 2020

Why has there been such a dip needs urgent attention of health policy makers including the national body such as National Organ and Tissue Transplant Organization (NOTTO). It is time to introspect and put the program back on track. The Times of India conclave on organ donation discussed the issue to some extent but can a

national task force be created to look at this worrying trend.

This newsletter issue also carries data on organ donation from India and other countries for comparison.

More organ pledges coming through driving license after a small change in the application

Since 2018, it has been possible in India to include your wish to be an organ donor on Indian driving license. However, the clause to pledge or not was so far optional. A simple smart move by Rajasthan transport department to make the clause compulsory and request for a change in the application, has meant

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Dr. Robert Montgomery's remarkable journey

The life of Dr. Robert Montgomery (58) is a beautiful and truly unique documentary that gives new hope to many transplant recipients across the world. Dr. Montgomery made history as a revolutionary kidney transplant surgeon. He saved the lives of thousands of patients by pioneering techniques that are still used today; but all along, he carried something dark and deadly inside his own body. Dr. Robert Montgomery is a professor of surgery and director of the NYU Langone Transplant Institute. In 1989, he became the first practicing surgeon in the world to receive an implantable cardiac defibrillator (a device that had just been developed at Johns Hopkins) as he suffered from familial dilated cardiomyopathy (a rare, progressive disease of the heart muscle that weakens its pumping ability and causes dangerous arrhythmias). A string of terrifying incidents left him no choice than awaiting a donor heart. His life-threatening symptoms got him priority status on the transplant list but alas his rare blood type (O) and uncommon size made him a tough match.

In 2018, 114,000 Americans needed an organ transplant, but only 36,500 received one. Dr. Robert Montgomery witnessed the nightmare of the transplant list first-hand. In order to improve the transplant rate, Dr. Montgomery and his team have been working to increase the number of organs available for transplant. He has helped with several initiatives that has increased the number of transplants for example domino kidney transplant, eight-way swap transplant. The use of livers infected with hepatitis C (HCV), the deadliest form of the virus, for that purpose is among the most promising. According to Dr. Montgomery, the new generation medications make it safe to transplant organs of all types from HCV-positive donors. The organs of people who died of opioid overdoses who are HCV positive can now be donated to those awaiting transplants.

Dr. Montgomery often told his team that he would take any heart they could find and that he doesn't care if the donor has needle in his arm as he strongly believed any transplant requires weighing the risks against the potential benefits. On 20th September a young, heroin overdose hepatitis C+ donor had been matched with him. He did not hesitate; he readily accepted to have the surgery. The surgery was performed by Dr. Nader Moazami (Heart Transplant Surgeon) and Deane E. Smith (Assistant Professor of Cardiothoracic Surgery and Associate Director of Heart Transplant and Mechanical Circulatory Support) at NYU Langone. In seven hours' time, the team removed the deceased heart, transplanted the healthy heart and closed the incision. Dr. Montgomery went home 10 days after the transplant and a course of medication cleared the virus from his system. Less than a week later he returned to work half-time and soon to his usual long hours. Like all transplant recipients, he takes a cocktail of immunosuppressant drugs to prevent organ rejection and other medications to fend off life-threatening infections. He's grateful for the chance to live that came with the donation, and glad to give back by advancing research on transplants that can have an impact around the world.

The story of first African-American to receive a Face Transplant

Since 2005, a mere 50 face transplants have been performed worldwide. Face transplants are rare, but Robert Chelsea (68) is different than most patients who received this procedure. He is the first African-American to undergo the procedure as his face was severely disfigured after a catastrophic car accident five years back. Refusing the first replacement face offered to him in May 2018, he spent a couple of years on a waiting list before his second face was ready.

The first time the face offered belonged to a man whose skin was much fairer and this made Chelsea think that this would give completely a different look and hence he declined. The second offer was his near perfect skin-color match. This made him both the first African-American to undergo a face transplant and the oldest recipient ever.

Because of mistrust of the medical system, many African-Americans are wary about becoming donors contributing to organ shortage; in turn, while 30% of white patients on the wait list received an organ, only 17% of black patients got one in 2015.

Marion Shuck, president of the Association for Multicultural Affairs in Transplantation (AMAT) said that having a visible, tangible reference, especially for African-Americans is so needed and Chelsea's story could inspire potential donors with transplant's positive impact.

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Kidney recipient ties knot to a kidney donor

In a heart-warming story, a bride and a groom from Uttarakhand who have unique stories to tell, tied the knot on 15th October 2021. While the bride (Asha) had donated a kidney to her brother, the groom (Abhinav) has been kidney transplant recipient about two years ago.

This is a rare case where the couple have special attachments towards each other as they both have one kidney. At first, both the families were apprehensive but the transplant surgeon who had operated on both the groom and the bride was quite confident that it is a safe option for them. "I tried to allay their fears as there is no problem in raising a family after marriage. They were convinced and agreed to tie the marriage knots," said Dr. Priyadarshi Ranjan, kidney transplant surgeon at a private hospital in Mohali. He added that this was first in his fifteen years career that he had encountered such case. This duo has taken organ donation to a new level and become a real-life example of how living organ donors and transplant recipients shall lead a normal life.

Union Health Minister Mansukh Mandaviya urges citizens to pledge organs

Every year in India, thousands of patients in need of an organ transplant die waiting for a suitable donor. Concerning that, the Union health minister Mansukh Mandaviya said India has to pick up pace to match the wide gap between the need and availability of organs for transplant. On 14th September 2021, a virtual event was organised by Times of India in association with Kokilaben Dhirubhai Ambani Hospital as part of their initiative – Times Organ Donation Drive, 2021.

The eminent panelists for the event were Dr. Naresh Trehan (Chairman of Medanta Hospital), Dr. Arti Vij (Head of Organ Donation Programme, AIIMS, New Delhi), Dr. Mohamed Rela, Chairman and Managing Director of Dr. Rela Institute and Medical Centre, Chennai), Dr. Sunil Shroff (Managing Trustee of MOHAN Foundation, Chennai), Dr. Santosh Shetty (Executive Director and Chief Executive Officer of Kokilaben Dhirubhai Ambani Hospital, Mumbai) and Dr. S K Mathur (President of Zonal Transplant Coordination Committee, Mumbai).

There were many suggestions to improve the donation rate in the country from the panellists. These included –

1. Dr. Trehan suggested requirement of sensitizing people and

doctors, devising internal hospital mechanisms for identifying brain-dead patients and approaching relatives for organ donation.

- 2. Dr. Rela felt that governments in all the states had the resources to boost organ donation and make transplant surgeries accessible to all.
- 3. Dr. Shroff said one strategy to boost the rate was to license all 540 government and private medical college hospitals for organ donation as they had the infrastructure to at least undertake organ retrieval. This would not only boost the numbers but also allow deceased donation to take place in all 28 states and 8 union territories in India rather than just 16 currently.
- 4. Dr. S K Mathur, spoke about the Maharashtra model wherein a multipronged approach involving hospitals' CEOs, intensivists and counsellors to increase organ donation numbers.

Union health minister Mansukh Mandaviya deliberated on the above suggestions and added that the organ donation campaign by The Times of India has the vigour, energy and the awareness which is required to save human lives.

Kannada Actor Puneeth Rajkumar's Eyes Donated to Four People

Superstar Puneeth Rajkumar from Karnataka became third in his family to donate his eyes (after his father, the legendary actor Dr. Rajkumar in 2006 and his mother Parvathamma in 2017), as his brother, Raghavendra Rajkumar took the responsibility to honor his epitome.

Puneeth had sworn to donate his eyes to Dr. Rajkumar Eye Bank, Narayana Nethralaya Eye Hospital, Rajajinagar, Bengaluru way back in 1994, which was launched by his father.

"Amidst the grief, Puneeth's brother Raghavendra Rajkumar called me and said that the family wants to donate his corneas. He was declared dead at 2.30 pm and the harvest was done at 2.45 pm. His corneas were intact. They will be used for needy patients at the earliest," says Dr. Bhujang Shetty, chairperson of Narayana Netralaya and head of Dr. Rajkumar Eye Bank.

Two corneal tissues were engrafted to four recipients using modern technology. "It is for the first time that such an experiment has been carried out successfully in Karnataka. The cornea of each eye was sliced into half, with the front portion given to one beneficiary and the second portion to another person. All the beneficiaries from Karnataka who have received the transplant are responding well after the operation", Dr. Bhujang Shetty told the media. With the many fans of the star following him, this is bound to spread awareness of eye donation.

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Organ Donation and Transplantation in India – What has happened in the last 10 years

It has been just over 50 years since the first successful organ transplant took place in India at Vellore, Tamil Nadu. The kidney transplant surgery, involving a living donor was performed by the doctors of Christian Medical College in 1971.

While India's transplant journey in the last 5 decades has been promising, the country's performance in comparison with its international counterparts remains a matter of concern. With the COVID-19 putting brakes on the transplant program world over, India too faced a fair share of challenges. The transplant program in the country is slowly picking up speed, with cities like Mumbai witnessing a surge in donations in the last few months.

Tracking the transplant progress over the last decade is important to appreciate the growth of the program. The living and deceased organ donor numbers are tracked in this issue from 2011 to 2020. These figures have been derived from the Global Observatory.

Country	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
Spain	6.77	8.31	8.63	9.43	9.07	8.05	7.53	6.81	7.67	5.77
Croatia	2.73	2.96	0.93	2.79	1.67	1.67	2.86	1.43	1.71	0.97
Belgium	6.94	8.06	9.46	9.64	7.87	9.65	8.42	7.83	6.21	5.00
USA	19.23	18.54	18.67	17.99	18.56	18.43	19.02	20.91	22.44	17.28
France	5.01	5.76	6.43	8.15	8.72	8.98	9.68	8.51	8.08	6.20
Norway	14.90	16.20	13.60	13.33	12.70	8.87	14.53	13.52	12.41	10.93
United Kingdom	17.04	17.01	17.91	17.78	16.65	16.13	15.62	15.82	15.58	8.54
Austria	6.89	7.50	8.95	9.06	7.88	8.02	8.27	8.75	10.11	5.78
Czech Republic	3.81	6.79	7.76	6.08	5.05	4.39	4.81	4.43	4.62	2.62
Sweden	20.31	17.06	16.25	16.36	13.57	13.84	12.93	14.41	14.88	11.49
India	4.41	4.41	3.32	4.64	5.10	5.09	5.54	5.97	7.74	4.67

Living donation rate (pmp)

Living donation rate was calculated with living donor kidney transplants and living donor liver transplants

Deceased donation rate (pmp)

Country	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
Spain	35.85	35.11	35.29	35.71	40.15	43.80	47.05	48.30	49.61	37.97
Croatia	33.64	34.77	33.49	35.12	40.24	39.52	33.33	40.24	31.95	25.37
Belgium	30.65	30.19	29.19	26.94	31.59	30.79	30.53	29.91	27.67	0.00
USA	25.95	25.79	25.83	26.65	28.21	30.76	31.70	32.81	36.07	38.03
France	25.83	25.86	26.02	25.93	28.09	28.73	29.74	28.85	29.37	23.15
Norway	25.92	23.40	22.20	22.75	21.35	20.94	21.89	19.26	21.30	18.89
United Kingdom	16.92	18.54	20.97	20.61	20.26	21.52	22.54	24.31	24.67	18.38
Austria	24.40	23.57	24.47	24.94	24.12	25.23	24.48	24.55	23.41	23.67
Czech Republic	17.62	20.38	20.37	24.39	23.43	25.33	25.38	26.60	27.17	23.27
Sweden	15.53	15.05	15.83	17.29	17.24	19.70	19.39	19.10	19.60	17.92
India	0.31	0.31	0.27	0.32	0.51	0.70	0.58	0.65	0.52	0.25

Deceased donation rate includes donation after brain death (DBD) and donation after circulatory death (DCD)

Statistics

Actual number of Living and Deceased Organ donors

Country	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
Spain	2007	2032	2060	2126	2269	2390	2532	2557	2658	2047
Croatia	160	166	148	163	176	173	152	175	138	108
Belgium	406	413	429	406	446	461	444	434	393	58
USA	14145	13996	14246	14400	15051	15944	16456	17556	19253	18308
France	1946	2008	2087	2201	2371	2440	2562	2436	2453	1917
Norway	200	198	179	184	177	158	193	177	182	161
United Kingdom	2119	2232	2453	2438	2388	2451	2526	2672	2697	1828
Austria	262	261	284	289	272	286	285	293	295	265
Czech Republic	225	288	301	326	299	313	320	329	337	277
Sweden	337	305	308	323	302	332	320	336	348	297
India	5680	5680	4493	6294	7355	7686	8202	8960	11319	6808

Actual number of organ donors includes deceased donors (DBD, DCD) and living donors (liver, kidney)

Actual number of transplants in India

Year	Kidney	Heart	Lungs	Liver	Pancreas	Small bowel
2011	4795	15	0	870	0	0
2012	4795	15	0	870	0	0
2013	4037	30	23	898	2	0
2014	5512	53	15	1327	10	2
2015	6555	118	51	1616	6	2
2016	6958	216	73	1754	28	1
2017	7334	237	106	1843	21	1
2018	7936	241	191	1945	39	2
2019	9751	187	114	2592	39	0
2020	5486	89	67	1780	26	7

Actual number of transplants includes transplants from both deceased donors and living donors

Source: http://www.transplant-observatory.org/ (as on October 29, 2021)

Editorial... continued from page 1

that one can't proceed further in the learner's license application process without expressing one's wishes.

In this issue we carry an interview with Mr. Mahendra Soni, IAS, Transport Commissioner, Rajasthan on how this move has had a positive impact on the number of people pledging for organ donation in the state.

There are 997 RTOs in the country that issue over 1.15 crore fresh or renewed driving licences every year. A rough calculation shows that on an average, 40 licenses are issued by each RTO on any working day. The impact of this initiative will help improve the organ donation in India in the times to come.

Ref: Shroff S, Navin S. You Can 'Pledge to be an Organ Donor' using the Driving License in India. Indian Transplant Newsletter. Vol.17 Issue No.54. July 2018-October 2018.



Interview

Organ donation clause in driver's license – Rajasthan's experience



Mr. Mahendra Soni Transport Commissioner, Rajasthan

The recent introduction of the organ donation clause in the driver's license in India enables an individual to make their consent on organ donation known. The Central Motor Vehicles (Third Amendment) Rules, 2018 has included the choice for an individual to pledge their organs while applying for the driving license. The Union Ministry has added a column in the first learner's application form for Driver's license about Organ Donation.

In this interview with Mr. Mahendra Soni, IAS, Commissioner, Transport Department Rajasthan, let's learn what extra steps did the state of Rajasthan took in order to make this initiative more effective and meaningful and what more can be done in the future.

What additional steps did your state department take when the Union Ministry of Road Transport issued an advisory asking all Regional Transport Offices (RTO) across the country to add a column in the application form for driving license in April 2018?

The central government's decision to incorporate the provision to include the option of organ donation in the Driving License was indeed a very welcome step. However, the option to consent or refuse was not compulsory in nature and an applicant could complete the form even if they had not responded to the organ donation column. As a result, many people were skipping this action thereby defeating the very purpose of the clause.

The Rajasthan Transport Department requested that this be made compulsory for an applicant to choose a 'Yes' or a 'No' for organ donation in order to complete the form. Without responding to this section, the application will not be accepted into the software. To skip the question is no more an option.

I feel this has encouraged people to give greater thought to the question and think a bit more deliberately about organ donation.

The software for driver's license services, Sarathi, is a uniform standardized software across the country. Can the states make any such changes at their level?

Yes, Sarathi is a pan India software but the Centre is kind enough to accommodate some changes at state level. Each state has its own requirements and some issues are very state specific, so certain changes with the Centre's permission are allowed at the state level. However, the clause on the learners 'Driving License' is the same in all states.

Where all has the option for organ donation been given?

The option to express the willingness to be an organ donor is not only while applying for a new driving license. It is also available while applying for a learner's license, a permanent driving licence, while applying for an address change, while applying for adding more vehicles to one's existing licence (for e.g. from a two wheeler to a four wheeler) and other such services.

For those who have a licence issued prior to this feature can also pledge to become organ donors when they go for a renewal of license or for updation of details on the document.

What has been the impact of these changes?

The impact has been very encouraging. Since September 2020, close to 2,75,000 people in Rajasthan have expressed a consent for organ donation while applying for any of these services. I feel that it is a significant number and the move will serve as a substantial step towards creating awareness and a discussion on organ donation.

How is a person's consent recorded on the licence?

The licence will bear an 'organ donor' logo along with a red heart in Rajasthan state issued licenses. The logo implies that the person has pledged his/her organs and in case of any mishap, the doctors can retrieve his/her organs after due consent from the family.

In other countries with this provision, the consent is recorded in a central registry that can be accessed at the time of accident or death of the applicant to see if they had consented to organ donation or not. This allows for the authorities to initiate the conversation with the family members. Are we looking at something on these lines in India?

I completely agree with you and if, in the long run, we are not able to dovetail the two i.e. individual consent with organ requirement, the entire exercise will be futile. There is absolutely no doubt that just recording the willingness to be a donor is not enough, forward linkages have to be worked out.

I feel that central guidelines on this would facilitate the process. Fine tuning and working out details can be done at the state level. It would help if Ministry of Road Transport and Highways could issue some enabling guidelines on this. Having said that, I am happy to take the initiative and look at this post Diwali.

What are your personal views on organ donation?

As an individual, I feel very strongly about this cause. I feel that nothing matches this kind of 'giving' – either by way of donating oneself or by enabling others to become donors.

LIFE...PASS IT ON

Interview

The queue of those waiting to get a lifesaving organ is very long, availability of organs is a real issue. One must work with one's full might to make organ donation a reality in our country.

I am not a technical person but I have learned that 9 lives can be saved with a single donation. What could be more powerful than this act? It is a matchless action, the greatest gift of all. Is there anything else you would like to convey to our readers?

The credit should go where it is due. If it was not for the efforts of MFJCF (MOHAN Foundation Jaipur Citizen Forum), the Transport Department would not have thought of these changes. It is the people on the ground who understand these issues better. Ms. Bhavna Jagwani and Mr. Rajiv Arora approached the department and insisted that these changes are crucial to make the Centre's ruling more effective and it is the synergy of MFJCF and The department that has resulted in these changes.

Transport Commissioner, Rajasthan Batch 2008 Previous assignments – Collector Jalore, Deputy Secretary to Chief Minister, Rajasthan

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Sd/-Sunil Shroff Date: 31[#] October 2021 Signature of Publisher

In the news – International... continued from page 2

Genetically Modified Pig's Kidney Successfully Transplanted into Man in an Innovative Experiment

The use of organs from pig to human represents a major breakthrough in medical treatment and has been in the experimental stage for over a decade now. Recently for the first time this was successfully performed in a human body.

In a risk-free procedure, a team of surgeons and doctors at NYU Langone Transplant Institute announced that they had performed the experimental surgery last month. They, after the consent from the family of a brain-dead deceased patient transplanted a kidney from a genetically modified pig, and it worked normally. The operation is the first successful attempt at kidney xeno-transplants in humans, and it raises the possibility that someday it would potentially become a renewable source for organs.

This experiment that lasted 54 hours has raised the hopes of many patients worldwide who are on long waiting lists to receive an organ. For now, research remains at experimental stage and has not yet been peer-reviewed nor published in a medical journal. "The kidney started to function normally, making urine and the waste product creatinine almost immediately. A pig organ that functioned outside the body is a strong indication that it will work in the body," said Dr. Robert Montgomery, the director of the N.Y.U. Langone Transplant Institute.

Donor lungs viable far longer when stored at warmer temperatures

The donor organs are used for therapeutic purposes, but their condition deteriorates quickly once they are explanted from the body. For years, scientists have used special ice packs to keep the organs cold till it has been transplanted into a recipient's body. A new study found that storing donor lungs at a slightly warmer temperature at 10 degrees rather than 4 degrees Celsius can make them viable for six times more as compared to traditional preservation methods for transplants.

"The finding may eventually change the practice and help erase some of the limitations that make it difficult for patients to receive successful and timely lung transplants," Marcelo Cypel, surgical director of the transplant program at University Health Network. Toronto General Hospital, where Cypel works, has now performed 40 such transplants as part of a clinical trial with lungs stored for up to 18 hours at 10 degrees Celsius which had shown excellent results.

In 1980s, studies out of Japan and Toronto made similar arguments, to no benefit, but now the idea is gaining new attention around the world.

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Recipient Story

Anudaan – Making Transplants Affordable



'Anudaan – Making Transplants Affordable' has been committed to making life saving organ transplantation accessible to all who need it in India. This initiative aims to enable and support financial assistance for organ transplantation for economically disadvantaged patients through crowdfunding. One becomes eligible for help under the Anudaan initiative for grant if their annual household income is less than or equal to Rs. 5 lakhs a year. The hospital is expected to offer support to the poor patient via a subsidized transplant cost, possibly under their CSR. Finally, the Anudaan Committee also reviews and evaluates overall funds that are raised through commitment by self, family, friends or through other Trusts or Foundations and understand the gaps and thereafter commit its support by acting as a bridging organisation.

Between July to October 2021, Anudaan has supported 5 underprivileged patients by providing them all with a new lease of life.



Sandya Debbati with her mother

Debbati. 21 years, Nizamabad, Telangana. Underwent

Ms. Sandya

kidney transplant on June 30, 2021 at Star

Hospitals, Hyderabad.

Anudaan contributed Rs. 1 lakh.

"Thank you so much MOHAN Foundation for giving me a new life."

– Sandya Debbati



Rohit Singh with his daughter

Anudaan contributed Rs. 1 lakh.

"My family and I thank MOHAN Foundation's Anudaan Team for supporting us in the time of adversity and helping us to get through the tough time. Our family will always be grateful to them."

Mumbai.

Pradesh.

- Rohit Singh Rajawat

Mr. Rohit Singh Rajawat,

33 years, Bhind, Madhya

Underwent kidney transplant

on July 30, 2021 at Bombay

Hospital and Medical

Research Centre,



Master Goutham BM, 3 years, Anantapur, Andhra Pradesh.

Underwent liver transplant on September 17, 2021 at Aster CMI Hospital, Bengaluru.

Master Goutham with his mother

Anudaan contributed Rs. 3 lakhs and worked with the hospital to bring down the transplant cost.

"I am very happy now. I would like to express my happiness and gratitude towards MOHAN Foundation for saving my son's life by giving financial support. Only because of MOHAN Foundation, my child is alive today. I am a poor lady, hardly able to feed my child, how could I then afford the transplant cost? Now both my son and I are happy and slowly trying to come to a normal life. My special thanks to MOHAN Foundation."

- Madhulatha G, mother of Master Goutham BM



Ms. Kaminiben Parmar, 23 years, Dohad, Gujarat.

Underwent liver transplant on June 22, 2021 at Aster CMI Hospital, Bengaluru.

Anudaan contributed Rs. 2 lakhs and worked with the hospital to bring down the transplant cost.

Mrs. Sherryna Contractor returned home

with Kaminiben after she "A young girl, who had to let go of all her dreams, her education, aspirations of a career, of marriage, of a future family just because she suffers from a rare liver

condition. We were aware that Kaminiben was fighting a rare liver condition. We have been supporting her medical treatment. Unfortunately, her health condition worsened and she required a lifesaving liver transplant. The cost of the transplant was something beyond most families reach and Mr. Shankarbhai could not have afforded the transplant. We approached MOHAN Foundation's Anudaan team for help and we are so grateful for their financial aid. Thank you so much for helping Kaminiben dream again."

> – Mrs. Sherryna Contractor – A well-wisher & supporter of Miss Kaminiben Parmar's family.

Mr. Gowtham Phanitej, 32 years, Khairatabad, Hyderabad.

Underwent kidney transplant on August 25, 2021 at Kamineni Hospitals, Hyderabad.



Gowtham with his wife

Anudaan contributed Rs. 50,000.

"It is my honour and pleasure to thank

MOHAN Foundation's life-saving initiative Anudaan from the bottom of my heart for supporting my husband financially during his kidney transplant. You are the only Foundation that came forward and helped us financially when we were in dire need. It means a lot to us. All of us are now very happy only because of your support. MOHAN Foundation gives hope to many people and we strongly wish that your foundation continues its kind support to many people in future. I wish your Foundation reaches greater heights."

- K. Shyamalatha, Gowtham Phanitej's spouse

Recipient Story

My Life is all about 10 percent what happens to me and 90 percent how I react to it



Ms. Neha Sharma, Senior Assistant in General Administration, Fortis Memorial Research Institute, Gurugram

I have had an unwanted relationship with hospitals and it was not primarily because I was born in one but because I spent 14 years of my life in hospitals. However, destiny had its own plans and it paved my way to become a transplant coordinator with one of the reputed hospitals in Delhi. Life is never easy for most of us, as we all have our own battles to fight and I am no different. I was born with severe urogenital illness and went through many surgeries as a child. As everyone, I too had my own dreams and ambitions and always aspired to work for Mass Media and Communication Industry. However, destiny had something else for me in the store. Soon after graduating, I was diagnosed with advanced kidney failure and straight away I was put on dialysis. From then onwards life was an uphill struggle for quite a few years. Each passing day was becoming painful, grueling, frustrating and tiring.

I was born different, being born with single kidney along with congenital urogenital malformations. I was quite a challenging case for doctors. I remember doctors telling my parents that my case was not easy and so was the success of transplant in comparison with other transplant patients. We all know the power of love and most powerful form of love one ever receives is from the super women who gives you birth. My mother, despite knowing about the low success rate and risks involved in my transplant, she not only gave permission to operate on me, but also became my donor. My family and my treating team never gave up on me which also gave me the strength to stay positive. There is a famous quote from Harry Potter which suits best on me and here it goes "Happiness can be found even in the darkest of times, when one only remembers to turn on the light". Together we beat all the odds and here I'm living my life like any other normal human being.

Apart from medications, everything became normal and my life was back on track. Though my dream to join mass media didn't come through, life gave me another chance to help others though my profession. I will always remain thankful to my doctors and nursing team who always supported me to stay positive and motivated. They say God never leaves you and is always there with you in different forms. It became true and I found one in Lt.Col. Sandhya Nair (Retired) who will always remain my inspiration. She is a highly motivated soul and whenever I see her, my heart just says one thing "Be like her". She is one of the major reasons for my motivation to become a transplant coordinator. She always tried to engage me with activities related to organ donation. My interactions with patients and their family gave me a different level of peace of mind and found the purpose of my existence. With her guidance and my determination, perseverance, grit and hunger to help the ones in similar situations, I became a transplant coordinator. It is rightly said that the secret of happiness is variety, but the secret of variety, like the secret of all spices, is knowing when to use it.

And here comes the father of all era I have known till date "The COVID Era". A time which blacked out almost everything for everyone. No stepping out, no family gatherings, parties, meeting friends, no socializing and complete isolation. It's a different kind of pain to see people dying everyday. It was even more hard for people with compromised immunity as there are more restrictions apart from isolation. Like many others, I too had to choose between my career and my health and obviously the choice was clear for me. I was devastated with this setback in my career. Days and nights did not feel any different. Like many, I got bored of my own thoughts and finally decided to do something productive and worthy with my time.

Being a recipient, I was curious to learn more about transplants, roles of immunosuppressive medicines, how and why organs get rejected, how dialysis works and what happens to people who do not get a donor organ. I got myself enrolled for a course with MOHAN Foundation. This course helped me learning the importance of transplant coordinators in hospitals and the entire process of organ donation. Nothing could be more fulfilling and content than saving someone's life especially if I could be a part of it. This transformed me to a new person with new dreams and passion. I feel proud to say that even COVID could not stop me. I fought my battle against COVID and this experience made me feel more strong and more positive about life than ever before. Simultaneously I completed my course as well and started applying for jobs.

"We are not fit for every job" as they say, but it's totally opposite in my case. The transplant coordinator profession always





Paintings by Neha Sharma

...continued on page 10

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LIFE...PASS IT ON

Donor Story

Case study – Importance of informing next-of-kin about organ donation pledge

for the retrieval.

On 6th October 2021, Ms. Ishwarya, Counselor of MOHAN Foundation received a call on the toll-free helpline number around 5.40pm. The caller informed that her 24-year-old nephew had died by suicide (hanging) around 1pm and was carrying an organ donor card of MOHAN Foundation. The deceased was an employee of Billroth Hospitals, Chennai. He was initially admitted to a private hospital and the family was asked to shift the body to the government Kilpauk Medical College (KMC) for postmortem after being declared dead.

The family called on the Foundation's tollfree helpline that was on the donor card of the deceased. The uncle and aunt of the deceased were informed that efforts could be taken for cornea and skin retrieval. They were also told that the immediate next-of-kin will have to provide consent for any donation that may take place. The family members were greatly distressed as they had been just informed that there would be a major delay in returning the body. The postmortem was to be performed only the next day as the forensic doctors had already left for the day, and the body was going to be retained in the mortuary.

Calls were made to Sankara Nethralaya for eye donation and Right Hospitals for skin as the counselor of KMC was not reachable. Clarity was sought on the possibility of tissue donation in these circumstances. The skin bank in-charge of Right Hospitals advised that it would be appropriate if the skin retrieval were to be done by KMC itself, which had an in-house skin bank available and helped with providing the contact of a Professor from the Plastic Surgery Department of KMC. The The situation seemed to be favorable towards tissue donation despite the initial hiccups in trying to coordinate the case remotely, only over phone. However, the family suddenly became unreachable in an unexpected turn of events. Multiple attempts to contact the family to

check on the status of donation were unsuccessful. It came to our knowledge the following day, through Sankara Nethralaya, that the mother of the deceased had unfortunately refused to provide consent for retrieval at the last minute. Both retrieval teams had arrived at the mortuary, only to have the Resident Medical Officer let them know that consent was not provided.

Professor when contacted, informed that he would have the technicians

from his department go to mortuary for retrieval. Technicians from

Sankara Nethralaya also had reached out to the family and were ready

This case study is an ideal example that illustrates the importance of informing one's family members about wishing to be an organ donor. The deceased was aware of the importance of organ donation, had pledged to be an organ donor and was carrying a donor card as well. However, this alone unfortunately did not serve the purpose as his immediate family was unaware of the deceased's wishes and could not fulfill them. It is of paramount importance that when someone pledges to be an organ donor, they inform their next-of-kin of their wishes to enable them to act when it really matters.

Recipient story... continued from page 9

demands you to be in healthy and fit. I went through a lot of refusals because of my transplant history. This used to pinch me hard, so I started distracting my mind with various activities like abstract painting and learning kathak. But I never gave up on myself as I knew that I could do this job just like any other person with more compassion; hence I kept on giving interviews.

Finally, I got a chance to prove myself and to fulfil my dreams passionately. The person who was completely aware about my limitations and boundaries but still accepted me was **Col. Dr. Avnish Seth** (Retired). He has not only given me a chance but also taken a bet on me **"To the soldier, luck is merely another word for skill"**. Shifting to a different city impacted on my health and I was infected many times. I thought of quitting but he had motivated me to fight with all odds. Under his guidance I have facilitated two deceased donations within a short span of time and this was a small and humble achievement of me.

At last, I would just say, 'nothing comes easy'.

Everything depends on your hard work, dedication and passion towards your dream. As a recipient I saw many hurdles in society and work culture. The people on dialysis are not aware of transplantation procedures. So, we should try to set an example for such people to move forward with transplant and have a better life. One should never give up on their dreams irrespective of the condition he/she is in. Hurdles will come and go but you have got only one life to live. God tests each one of us at some point or other in our lives but believe me this is His way to see how strong you are and passionate about your dreams. Aspire so that you can inspire people to live!!!!



Collaboration & Award

Transplant Pregnancy Registry International – An Opportunity for Collaboration

Transplant Pregnancy Registry International – an Opportunity for Collaboration with India



Ms Kannika Jain had her son Veer 5 years after her kidney transplant, he is now 3.5 years old

The Transplant Pregnancy Registry International (TPRI) is an international organization specializing in studying pregnancy after solid-organ transplantation and to be a resource to the transplant community regarding parenthood after transplantation. TPRI is the longest running voluntary pregnancy registry in the world, which has been collecting pregnancy information for over 30 years.

The first known post-transplant pregnancy occurred in a female recipient in 1958. Both the donor and recipient who were twin sisters went on to have successful pregnancies. TPRI began collecting data internationally since 1991 and now has recipients from over 20 different countries, encompassing more than 2,800 recipients who have reported over 5,000 pregnancy outcomes. TPRI uses a multi-pronged data collection approach involving telephonic interviews, reviewing of medical records and long-term follow-ups.

India currently has one recipient who is part of TPRI, and in an effort to increase the Indian data, MOHAN Foundation along with NATCO (Network and Alliance of Transplant Coordinators) and ISOT (Indian Society of Organ Transplantation) invited Ms. Lisa A. Coscia, Senior Registry Research Coordinator-Transplant Pregnancy Registry International, Philadelphia (USA) to speak at the 14th Annual International Conference of NATCO and the 31st Annual Conference of the Indian Society of Organ Transplantation & to help increase the understanding of the Registry and to discuss ways to partner to represent the data from India.

Studying pregnancy outcomes by country and comparing outcomes across countries is an exercise TPRI wishes to undertake in the future to help its patients better. With additional pregnancy outcomes, TPRI will be able to continue to educate healthcare professionals and recipients enabling them to make informed decisions about parenthood after transplantation. MOHAN Foundation and TPRI have undertaken to partner to capture data of Indian transplant recipients and seeks the participation of hospitals, transplant professionals and coordinators for the same.

Times Organ Donation Drive

Award

In a unique move, the Times Organ Donation Drive (an initiative by Times of India) felicitated some of the corporates who have been supporting the cause of organ donation in India. This was the first time in India that such a felicitation was done on any platform.



Gurshaan Singh, Associate VP – Marketing & Internet, Ethos Watch Boutiques

Kim Verma Modi, President & Managing Trustee, Verma Medicine Research Trust

Times Organ Donation Drive is an initiative by The Times of India, in partnership with Kokilaben Dhirubhai Ambani Hospital, to create awareness on organ donation, encourage people to sign up as organ donors and to influence policy. The felicitation ceremony was held on 3rd September, 2021 at Kokilaben Dhirubhai Ambani Hospital and it was also made virtual through Zoom for the participants who could not attend the face-to-face ceremony. Ms. Sonali Bendre Behl (Actress) was the Guest of honour.



Ms. Pallavi Kumar, Executive Director, MOHAN Foundation-NCR speaking at the event

Some of the corporates felicitated during the ceremony were Dalmia Bharat Limited, Edelweiss Tokyo Life Insurance Co. Ltd, Ethos Watch Boutique, Sanofi Healthcare Pvt Ltd, SBI Foundation, Tata Trusts, Verma Medicine Research Trust, Worley Services India Pvt Ltd, Willis Towers Watson India Pvt Ltd, Ganesh Housing Corporation Ltd, Prakash Asphalting's & Toll Highways (PATH) India Ltd. Many of these corporates have been partnering with NGOs for many years helping raise public awareness, train medical and paramedical staff in making organ donations happen in their hospitals, starting work in newer states or simply supporting innovative ways to raise public consciousness in organ donation – like the Angdata Smarak in Jaipur (the first of its kind public art installation in organ donation).

Training Programme

One-month Online Transplant Coordination Professional Certificate course successfully conducted in July, August and September 2021



Participants with faculty and organisers – July 2021



Mrs. Mayuri Barge, Manager – Organ Transplant Program, Dr. D. Y. Patil Hospital (Pune) explaining obtaining informed consent for organ donation – August 2021



Mr. Santhosh Gnanasekaran, Transplant Coordinator, Fortis Healthcare, Chennai moderating roleplay – September 2021



Ms. Sabina Hardman, UK (observer) sharing her views on ethical aspects of organ donation and transplantation – September 2021

The one-month online 'Transplant Coordination Professional Certificate' course was successfully conducted in the months of July, August and September 2021. The participants were from various parts of India as well as one from Kuwait. Experienced transplant coordinators across the country were invited as faculty during weekend webinars. A total of 87 candidates completed the course in these three batches and received their certificates.

Feedback

My experience of 'Transplant Coordination Professional Certificate" has been simply amazing. The depth to which Transplant coordination was explained to us was very impressive. Webinars were really informative and interactive with case discussion and role play. I am really happy to have taken this course. The faculty is really nice and inspiring. I wish to follow on their footsteps and do justice to this profession.

- Dr. Megha Thapa, Physician Assistant, Apollomedics Super Speciality Hospital, Lucknow

Special Event

COVID-19 Made Radio a Popular Medium in Creating Organ Donation Awareness



An AIR interview in progress

Dr. Teena Sawhney interviewed at AIR Jaipur

Celebration of 'Organ Donation Week'

Ms. Sunayana Singh of ORGAN India at the AIR Station

'Necessity is the mother of invention' - Plato

As technology took over the reins during the pandemic, staying connected with the masses and awareness creation in remote locations were becoming challenging. Innovation was the need of the hour and what came to rescue was a medium of communication that was in vogue before the advent of internet – the Radio.

MOHAN Foundation Jaipur Citizen's Forum (MFJCF) had been visiting gram panchayats of Rajasthan to create awareness about organ donation, however the campaign came to a complete halt as the pandemic arrived. Undeterred, the team switched to All India Radio's Gram Bharti program from April 2021. A short play on the importance of organ donation, followed by interviews with experts is being broadcast every month, effectively tapping the rural population of the state. Ms. Bhavna Jagwani, Convener – MFJCF says, "Radio is the easiest tool for communication, wherein a shepherd who is grazing cattle or a woman working in the farm can listen to and absorb the information. Hence this is the best outreach program to touch base with the rural population of the state, as 90% of the donors are from rural Rajasthan."

In Tamil Nadu, a one-month long campaign was broadcast in the month of September 2021 on Arasu FM – the community radio channel of Arasu Engineering College, Kumbakonam. Similar awareness campaigns were broadcast in August 2021 on the community radio channels of Anna University, Chennai and National Institute of Technology, Trichy. Dr. Hemal Kanvinde – Quality Assurance Officer, MOHAN Foundation said, "Community radio is the most effective medium to create awareness among targeted communities."

AIR Rainbow FM Jalandhar invited Mr. Sudhir Dewan – Honorary Director of MOHAN Foundation to deliver a talk on eye and organ donation in September 2021. The radio show covered many districts of Punjab, Himachal Pradesh and Jammu & Kashmir, covering a population of around 130 million. Since then the Chandigarh office has received many phone calls as far as from Lahore, enquiring about the process of organ donation.

A community radio project conceived in 2019 by ORGAN India is now being aired also on AIR FM, covering almost whole of Haryana, Vidisha and Dharamshala. The episodes in Hindi feature theme-based interviews and call to action for the listeners. The episodes have been broadcast in 4 different channels, reaching out to crores of listeners. "Our Radio campaign is aimed at mass dissemination of information. We have found it to be extremely impactful. In terms of reaching out to the local population wherever it is aired. Shows create impact by driving traffic to our website, lead to increase in pledges from areas where shows are aired and in also in the increase in helpline calls from those areas. Radio stations that are broadcasting the shows (whether it's AIR or Community Radio Stations) often broadcast in areas where there is very little awareness on organ donation, and they receive lots of calls and good feedback from listeners. I urge others to do the same in other states to increase mass awareness on the subject," said Ms. Sunayana Singh - CEO, ORGAN India about the effectiveness of radio.



Photography competition – First prize winning entry – Arish Kumar

All the offices of MOHAN Foundation observed Organ Donation Week from August 7 to 13, 2021. Multiple awareness talks, online sessions, stalls, information desks, Rangoli Competition, Photography Competition were organized to reach out to maximum number of people so that everyone is sensitized to the need of the hour and more and more people can come forward and pledge their organs.

In addition, multi-city sensitization sessions or events on organ donation were organized on online platforms like Facebook, YouTube & Zoom for participants belonging to the cities of

Delhi, Chandigarh, Jaipur, Mumbai, Nagpur, Indore, Dhule, Bengaluru, Belgaum, Chennai, Hyderabad & few from USA & Saudi Arabia. 3888 people were reached through 47 awareness sessions/events held in this week.



Rangoli Competition held for nursing staff of Indira Gandhi Government Medical College & Hospital (IGGMCH) Nagpur

Conference

NATCO's 14th Annual International Conference held virtually under the aegis of ISOT



Dr. A G Huprikar delivering the inaugural address

Dr. Sunil Shroff (center) and Dr. Vivek Kute (right) launching the new NATCO website

Dr. Vasanthi Ramesh making her remarks

Ms. Manjula Kalyanasundaram annoucing the winners

Network and Alliance of Transplant Coordinators (NATCO), in association with MOHAN Foundation, under the aegis of Indian Society of Organ Transplantation (ISOT), held its 14th Annual International Conference on October 8-9, 2021. The conference was held virtually and was supported by ZTCC (Zonal Transplant Coordination Committee) Pune and SBI Foundation.

The theme of the conference this year was **'Towards Newer Horizons**' to help participants look beyond the pandemic and continue to put all their energies and efforts to augment organ donation and transplantation in India.

The conference covered a wide range of topics under the following broad themes:

- Organ Donation & Transplantation during the COVID-19 Pandemic
- Paediatric Organ Donation and its Unique Challenges
- Learning from International Experiences

Around 100 national and international delegates including transplant coordinators, NGO representatives and individuals working towards promoting the cause attended the conference. Speakers, chairpersons and panel members were eminent professionals from the fields of medicine, government departments and academia from all over the world.

The inaugural ceremony on evening October 09, began with an invocation by Mr. Sandeepan Arya of Muskaan. Ms. Arati Gokhale, President of NATCO delivered the welcome address and Ms. Surekha Joshi presented the secretary's report. Dr. A G Huprikar (Secretary, ZTCC Pune), the Chief Guest for the occasion, appreciated the work of NATCO and MOHAN Foundation and expressed his gratitude to the transplant coordinators who keep the deceased donation program going. Dr. Vivek Kute (Secretary, ISOT) and Dr. Sunil Shroff (Managing Trustee – MOHAN Foundation) launched the new website of NATCO, congratulated the organisers and wished the conference success. Dr. Vasanthi Ramesh, Director of NOTTO, chaired a session on Day 2 and appreciated the topics chosen for the conference.

Paper presentations by transplant coordinators (international and domestic) kicked off the conference. Mr. Howard Nathan, President & CEO, Gift of Life Donor Program, USA, delivered the Swamy Naryan Memorial Oration. Mr. Nathan spoke about his journey in the transplantation field – starting out as a transplant coordinator to heading the nation's largest organ procurement organisation, and how the program has evolved in the US.

The following topics were discussed and debated during the conference:

- Transplant Pregnancy Registry International an Opportunity for Collaboration between TPRI, ISOT and NATCO
- Unique Partnerships with Government Departments
- New NGOs on the Block undertaking work on organ donation
- Corneal Donation getting back on track with COVID-19 Pandemic (Guidelines and Protocols)
- Protocol on Body Donation during COVID-19 Pandemic
- Challenges of Coordinating Donations during COVID-19 Pandemic – Sharing by Transplant Coordinators
- Owning the Deceased Organ Donation Program in COVID-19 Pandemic – A Hospital Team perspective
- From Uncertainty to Newer Horizons NGO speak
- Best Practices to Improve Donation Rates Experience sharing by International Experts
- Directed Donation Is the Donor the Owner
- Challenges of Counseling in Pediatric Donations
- My Experience with Pediatric Donation Invited Case Discussion by Transplant Coordinators
- Caveats in the Psychological Evaluation of Face Transplant Candidates

The Valedictory ceremony on the evening of October 10 began with a prayer rendered by Mrs. Lalitha Raghuram – Country Director of MOHAN Foundation and Former President of NATCO. She welcomed the Chief Guest Ms. Manjula Kalyanasundaram, Managing Director & CEO of SBI Foundation and thanked her for the support. Ms. Kalyanasundaram acknowledged the efforts of the organisers and appreciated the determination and commitment of the transplant coordinators.

Three nominees for the Swamy Narayan Best Transplant Coordinator Award, presented their work from past year and Ms. Prarthana Dwivedi of Indira Gandhi Govt. Medical College Hospital, Nagpur bagged the award. The winners of the free paper presentation were:

- Dr. Omid Ghobadi from Iran: A successful solution to prevent the decline of the training effect of organ donation teams
- Dr. Marzieh Latifi: The effect of acceptance and commitment therapy (ACT) on grief symptoms of organ donors' mothers

Conference

Ms. Sunayana Singh: Radio – The way Forward for Mass Information Dissemination on Organ Donation

Ms. Kalyanasundaram announced the winners and congratulated them. Vice President of NATCO, Ms. Pallavi Kumar thanked everyone, requested the audience to use the website and other resources and work to increase the membership of the organisation. A participant from Pakistan mentioned that the conference would really help countries like her own learn many best practices and benefit from the knowledge sharing. Mr. Sandeepan Arya also highlighted the many new learnings in his feedback.

Dr. Hemal Kanvide (NATCO Member, South Zone) delivered the formal vote of thanks with the recital of a Tagore's poem. The conference came to close with a group picture being clicked and attendees departing with hope of meeting each other soon.

BECOME A NATCO MEMBER TODAY

A well trained and knowledgeable transplant coordinator is vital for a successful organ donation and transplantation programme in any transplant centre. As more and more hospitals take up organ donation and transplantation activities in India, and newer advancements are being made in the field, it is highly essential for the transplant coordinators to constantly develop, upgrade their skills and stay abreast with the changes.

NATCO, through its conferences and workshops, offers huge opportunities for you to upgrade your soft skills as well as technical knowledge in this field. The conferences and workshops are topical, relevant and are uniquely designed to address the demands of this profession in India. They also brings to you achievements and knowledge from all over the world. These conferences enable interactions with some of the senior most transplant experts, both national and international. The meetings serve as an opportunity for building a professional network and camaraderie between the transplant professionals.

Please visit www.natco.org.in to know more and take up membership

In the News – National ...continued from page 3

Two brain-dead donors save fourteen lives in Karnataka

On 16th August 2021, Lawrence (40) from Hunsur and Shobha (48) from Kushalnagar met with a road accident and suffered severe head injuries. They had been moved to the Intensive Care Unit at BGS Hospitals, after being in another private hospital in Mysuru. Despite all efforts to save them, both the patients were declared brain dead, said N.G. Bharateesha Reddy, Vice-President and Unit Head, Apollo BGS Hospitals, Mysuru. The two deceased became potential donors after both their family members voluntarily gave their consent. The organs were retrieved and distributed to the waitlisted patients under the aegis of Jeevasarthakathe and State Organ and Tissue Transplant Organisation.

Two Friends hailed as heroes for organ donation after they became brain-dead at Surat

Death did not stop the friendship of two friends from becoming immortal. Meet Pandya (18) and Krish Gandhi (19) helped give a new lease of life to save 13 end-stage organ failure patients by donation of their vital organs.

Meet and Krish from Surat were best friends since their childhood. On August 24, the two friends met with a serious accident and suffered from brain haemorrhage. Despite the best efforts the doctors could not save them and they were both declared brain dead on August 28. The two grieving families despite their personal loss said yes to organ donation. Donate Life, Surat based NGO facilitated the organ donation process and four kidneys, two livers, one heart, two lungs and four corneas were retrieved. Four green corridors were orchestrated to distribute the vital organs to different destinations at Hyderabad and Ahmedabad. "This was the first case in the state where as many as 13 organs and tissues that were donated and transplanted at one go and lives of many organ failure patients were saved," said Mr. Nilesh Mandlewala, Founder and President of Donate Life.

PROJECT **GIFT HOPE, GIFT LIFE**

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"The SBI - MOHAN Foundation Organ donation Helpline is an important initiative in the organ donation ecosystem as it acts as a bridge between its various stakeholders - public, patients, police and professionals from healthcare.

It completes the loop and gives clarity to the public as to where to reach out for any sort of information. It is commendable that what started off as an information-giving tool has now been coordinating organ and tissue donations, and more than 200 lives have been saved and approximately 46,000 beneficiaries have been counselled under the initiative".

Shri. Lalit Mohan President & COO, SBI Foundation

SBI - MOHAN Foundation Organ Donation Helpline - 1800 103 7100



World Trade Centre, No. 35, Ground Floor The Arcade, Cuffe Parade, Mumbai, Maharashtra - 400005 www.sbifoundation.in

AVERAGE LANGUAGE DISTRIBUTION

FREQUENTLY ASKED QUESTIONS

- I want to donate my organs, what is the process?
- Can I register for cadaver transplant in another state?