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### Editorial Desk

### **Commonwealth Tribute to Life Project**

On the Commonwealth Day, which falls on 14<sup>th</sup> March 2022, we will witness the launch of an important initiative on organ donation and transplantation for the commonwealth nations entitled Tribute to Life. The 54 commonwealth countries are home for about 2.6 billion people which represents one-third of the world population.



Commonwealth Tribute to Life Project – Logo

The objective of this voluntary initiative is sharing of knowledge and expertise to promote ethical organ and tissue donation and transplantation, regardless of transplant infrastructure, for the benefit of all Commonwealth citizens. These benefits include –

- 1. Gaining of knowledge through the sharing of guidelines, protocols, teaching material, mentorship and training via self-funded sabbatical
- 2. Supporting progress in those nations where organ transplantation is well established, but where there is continued unmet need in more ethnically diverse communities
- 3. Exploring the potential for commencing transplantation in countries where it does not
- 4. Encouraging Commonwealth citizens to participate in activities related to their country of historical origin, and also share with them success stories from their country of origin
- 5. Protecting vulnerable Commonwealth citizens against illegal and unethical transplantation and saving and transforming the lives of thousands of patients

The initiative is open to members of commonwealth countries and one can join as Country Representative, Senior Clinicians from Commonwealth Country in the field, Medical Society with interest in organ donation and transplantation or Paramedical Coordinator – with interest in organ donation and transplantation – (https://docs.google.com/forms/d/e/1FAIpQLScJBK 5dfgys2gwxC6c-0uc2wWkzFH-CyBzrstczjHDso8HxQ/viewform)

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# In the news – International

### First Successful Pig-to-Human Heart Transplant

The transplant world witnessed a breakthrough with the first successful animal-to-human transplant performed on a 57-year-old man from Maryland. This first-of-its-kind transplant was performed at the University of Maryland Medical School, Baltimore in January 2022. David Bennett Sr. had been on cardiac support for almost two months. However, he could not receive a conventional transplant due to his health condition and other reasons. On New Year's Eve, the United States Food and Drug Administration approved an emergency surgery and Bennett agreed to undergo this experimental treatment as he would have died without a new heart.

The heart came from a genetically modified pig that had ten genetic modifications. Three genes in the donor pig responsible for rapid antibody-mediated rejection by humans were knocked out. In addition, six human genes responsible for the immune acceptance of the pig's heart were inserted into the pig's genome.

One more gene from the pig was removed to prevent excessive growth of the pig's heart tissue after being transplanted into a human.

"This was a breakthrough surgery and brings us one step closer to solving the organ shortage crisis. There are simply not enough human organs available to meet the long list of potential recipients," said Bartley P. Griffith, the director of the cardiac transplant program at the University of Maryland Medical School, who performed the transplant surgery on Bennet.

Xenotransplant shall potentially offer new options for patients with endstage organ damage, but this may also face ethical considerations including choosing suitable patients for such transplants, long-term transplant outcomes, and the risk of infections transmitted from animals to humans.

# An Indian-Origin Organ Donor in Singapore Receives a Prestigious Award for Saving a Baby's Life

The Straits Times Singaporean of the Year 2021', a prestigious award by the Singapore Government was conferred upon Sakthibalan Balathandautham, an Indian-origin Singaporean sales executive for donating a part of his liver to a one-year-old girl whom he had never met before. The award included a trophy and 20,000 Singaporean dollars was presented by President Halimah Yacob in February 2022.

A young Indian couple posted a plea on social media seeking a liver donor for their one-year-old daughter Rheya, who had been diagnosed with biliary atresia. It is a rare liver disease that occurs in infants and often found shortly after birth. Responding to the plea, Sakthibalan Balathandautham donated 23 per cent of his liver to baby Rheya.

At the award ceremony, President Halimah Yacob stated that the finalists had reminded Singaporeans of the importance of serving a greater purpose. "It was inspirational to all of us to see Sakthibalan's act of courage, generosity, and willingness to put his own health and well-being at risk while helping others. He is indeed deserving of this award," she added.

When asked why he had stepped forward, Sakthibalan said, "There's a young girl out there who is looking for a living liver donor. I felt it would be the right time for me to participate in something bigger." Sakthibalan is now an advocate for organ donation, encouraging as many people as possible to support organ donation and help patients in need.

#### FORM - IV

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Sd/-Sunil Shroff

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Signature of Publisher

# The Stool of a Healthy Person Helped to Cure a 78-Year-old Man Suffering from Persistent Diarrhoea and Bleeding

Doctors from Sir Ganga Ram Hospital, New Delhi treated a 78-year-old patient with Faecal Microbiota Transplant (FMT), a procedure in which stool from a healthy individual was put into the patient's colon. This 78-year-old patient was admitted with recurrent inflammation of the large intestine and bloody diarrhoea. His stool examination showed persistence of Clostridium Difficile, which has led to Pseudomembranous Colitis (PMC).

The gut microbiome plays a pivotal role in maintaining good health and the imbalance between the good and harmful bacterial species is linked to various diseases. 'Transplanting stool from a healthy person became the only viable option for him as FMT would help increasing good bacteria in his intestine' said Dr Piyush Ranjan, vice-chairperson, Institute of Liver Gastroenterology & Pancreatico Biliary Sciences, Sir Ganga Ram Hospital. It was reported that the patient was doing well after receiving the transplant in November 2011.

Expert comment: 'Fecal Microbiota Transplant (FMT) or Stool Transplant is the next big thing in medicine. Dysbiosis or imbalance between good and bad bacteria in the intestine has now been implicated in the causation or progression of several diseases. Clostridium difficile infection was one of the first diseases to be treated with FMT and is the standard of care the world over. It is good to see that more and more institutions are now performing FMT in India. We did the first stool transplant of the country in 2014 and have done over 150 such procedures. We are currently studying its role in patients with Ulcerative Colitis, Crohn's Disease, Irritable Bowel Syndrome, Alcoholic liver disease, Metabolic syndrome including obesity, Parkinson's disease and Autism Spectrum Disorder', Dr (Col) Avnish Seth, VSM, Head, Department of Gastroenterology & Hepatology, Manipal Hospital, Dwarka, New Delhi, Head, Manipal Organ Sharing & Transplant (MOST)

### **NIMHAN's First Deceased Organ Donation**

National Institute of Mental Health and Neurosciences (NIMHANS), the country's premier centre had its first deceased donor organ retrieval in February 2022. Ms Chaitra K.R, a 26-year-old resident from Kolar district was all set to tie the knot on February 7, 2022. But destiny had other plans for her. During her wedding reception photo shoot, Chaitra collapsed on the stage and was rushed to NIMHANS. Chaitra suffered a brain stroke and all the efforts to save her were futile. On February 11, 2022 doctors at NIMHANS declared Chaitra as brain dead. Amid the tragedy, the bride's parents consented to donate her organs that saved many lives. Chaitra's corneas and heart valves were donated and distributed to the transplant centres by Jeevasarthakathe, the State Organ and Tissue Transplant Organisation (SOTTO).

This was the first deceased organ donation from NIMHANS two years after receiving licence to function as a Human Organ

Retrieval Centre (HORC). Dr. K. Sudhakar, Hon'ble Minister, Health and Family Welfare, Government of Karnataka said in a tweet, "This is a noble gesture and it should be a role model to everyone."

NIMHANS Resident Medical Officer (RMO) Shashidhara H.N. said so far if a brain death occurred in the hospital, the body was shifted to a transplantation centre. "Although the National Organ and Tissue Transplantation Organisation (NOTTO) authorised NIMHANS as a non-transplanting organ retrieval centre in 2020, we could not take up retrieval of organs because of logistical concerns. However, we were able to do this on Friday in coordination with Jeevasarthakathe, the State Organ and Tissue Transplant Organisation (SOTTO), and MOHAN Foundation," the RMO said.

# Two Kidney Recipients from Karnataka Tie the Knot on Valentine's Day

Valentine's Day has showcased many examples of couples celebrating love. One such was from Avinash Shekar and Pavithra Vani, the two kidney transplant recipients who tied the knot on February 14, 2022 in Bengaluru. Avinash Shekar and Pavithra Vani, both aged 30 knew each other from the time they were treated for their renal problems at a private hospital. However, their friendship grew into love when they started working in the same tech park.

While Avinash Shekar received his transplant twice from his relatives, Pavithra Vani's transplant was from a deceased donor.

Avinash Shekar's first transplant was from his mother, but it was unsuccessful. His second transplant was in 2015, with his aunt being the donor for him. Avinash's father was also a kidney donor who donated his kidney to his brother-in-law, 32 years ago.

"There is still not much awareness about organ donation and there is fear associated with it too. If others see people like us, they can understand that there is life beyond organ failure and awareness about organ donation will spread," said the groom.



# Kidney Transplants around the World

## Kidney transplants (Living donor and deceased donor kidney transplants)

Country	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
USA	17610	17286	17657	17815	18597	19858	20638	22003	24273	23644
China	5540	5540	5540	5540	7040	9019	10793	13029	12124	11037
Brazil	4957	5387	5409	5507	5510	5600	5946	5975	6298	4830
Spain	2498	2551	2552	2678	2905	2997	3269	3313	3423	2702
France	2976	3044	3074	3232	3486	3615	3782	3567	3643	2595
United Kingdom	2752	2899	3257	3201	3173	3328	3448	3642	3649	2567
Turkey	2942	2905	2944	2932	3204	3423	3342	3874	3863	2498
Republic of Korea	1287	1783	1760	1808	1891	_	2163	2108	2293	2280
Germany	2850	2586	2272	2128	2196	2094	1921	2291	2132	1909
Italy	1751	1786	1715	1840	1881	2076	2246	2124	2139	1907
Japan	1601	1605	1322	1598	1629	1648	1640	1865	1913	1697
Canada	1236	1321	1342	1336	1437	1732	1771	1706	1790	1518
Iran	2273	2420	2670	2325	2531	2477	2282	2263	2101	1240
Mexico	2468	2646	2707	2610	2770	2971	3166	3081	2976	913
Argentina	1097	1184	1274	1277	1198	1150	1321	1475	1675	854
India	_	_	4037	5512	6555	6958	7334	7936	9751	5486

Source: http://www.transplant-observatory.org/ (as on 21st January 2022)

## Deceased donor kidney transplants

Country	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
USA	11838	11669	11924	12279	12969	14229	14827	15561	17406	18410
China	4577	4577	4577	4577	4931	7224	9040	11302	10389	9399
Brazil	3314	4051	4226	4453	4493	4400	4807	4942	5227	4385
France	2674	2687	2673	2718	2939	3039	3171	3026	3133	2443
Spain	2186	2190	2170	2255	2517	2654	2937	3020	3088	2205
United Kingdom	1726	1867	2157	2104	2131	2310	2448	2608	2627	2009
Italy	1540	1593	1498	1589	1578	1796	1933	1831	1799	1623
Germany	2055	1820	1547	1508	1551	1497	1364	1653	1612	1459
Canada	803	850	_	884	992	1260	1299	1219	1256	1122
Russian Federation	796	746	747	836	755	852	973	1161	1290	967
Republic of Korea	491	768	750	808	901	_	903	807	794	848
Iran	771	914	1169	1122	1433	1399	1351	1245	1354	820
Argentina	848	901	874	897	812	746	929	1099	1324	724
Poland	1035	1094	1105	1094	987	1058	1035	906	931	720
Australia	570	606	630	637	703	821	832	897	857	704
India	_		542	628	984	1261	1169	1164	1138	516

Source: http://www.transplant-observatory.org/ (as on 24<sup>th</sup> January 2022)

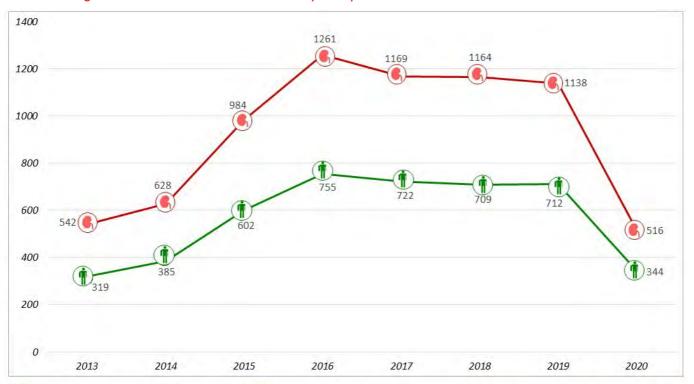


#### Living donor kidney transplants

Country	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
USA	5772	5617	5733	5536	5628	5629	5811	6442	6867	5234
Turkey	2421	2381	2359	2298	2534	2639	2649	3015	3055	2249
China	963	963	963	963	2109	1795	1753	1727	1735	1638
Japan	1389	1412	1167	1471	1462	1471	1442	1683	1683	1556
Republic of Korea	796	1015	1010	1000	990	_	1260	1301	1499	1432
Mexico	1889	1948	1960	1862	1960	2120	2234	2105	2050	630
United Kingdom	1026	1032	1100	1097	1042	1018	1000	1034	1022	558
Saudi Arabia	431	506	462	514	618	673	776	865	981	477
Germany	795	766	725	620	645	597	557	638	520	450
Brazil	1643	1336	1183	1054	1017	1200	1139	1033	1071	445
Iran	1502	1506	1501	1203	1098	1078	931	1018	747	420
Canada	433	471	_	452	445	472	472	487	534	396
France	302	357	401	514	547	576	611	541	510	390
Netherlands	440	485	520	534	514	565	551	510	501	367
Pakistan	855	855	855	327	361	915	1003	1122	1306	129
India	_	_	3495	4884	5571	5697	6165	6772	8613	4970

Source: http://www.transplant-observatory.org/ (as on 25<sup>th</sup> January 2022)

#### Deceased organ donors and deceased donor kidney transplants in India





Deceased organ donors Source: http://www.transplant-observatory.org/



## Tough Times Do Not Last, Tough People Do



Mr. Bharath Kumar

#### **Background & Career**

Born in Tumkur, Karnataka, 33-year-old Bharath Kumar came from an agricultural family background. He earned his diploma in Mechanical Engineering from Tumkur district, after which he pursued an engineering degree from Mangalore. He began his career as an associate engineer for a company in Bengaluru. His diligence and dedication earned him

a promotion to Senior design

engineer and thus began his career with a lot of great opportunities, which in turn opened the doors for him to travel to the United States on various assignments and training.

#### **Beginning of Health Challenges**

In 2010, one fine day, he was rushed to the hospital with complaints of severe abdominal pain. The doctors detected ureteral stones in his kidneys and he was advised to have the stones removed. During this procedure, he was diagnosed with Portal hypertension (increased pressure in the portal vein, which carries blood from digestive organs to the liver) and liver related concerns were highlighted. He was put on some medications and was told not to worry as it was not life-threatening.

Life went on and in 2012, during one of his health checkups, Bharath's ANA (Antinuclear Antibody) test came positive. Around this time, he faced several health complications including high blood sugar and frequent urination. After undergoing more tests, he was diagnosed with Type 1 Diabetes and he was put on insulin for management of blood sugar levels. Bharath managed to balance work and health inspite of the ups and downs.

Around 2017, Bharath began to notice that his stomach was getting enlarged. He was advised to regularly undergo ascitic fluid tapping for draining the fluid. Visits to hospitals and check-ups became more frequent. During 2019, when he was in United States, on a work assignment, he began noticing edema (swelling caused by water accumulation) on his body and experienced severe abdominal pain. He immediately underwent tests in a hospital in US and the doctors there gave him medications, while also suggesting that he return to India immediately and pursue treatment under his doctors.

#### **Turmoil & Liver Transplant**

Bharath rushed back to India and his doctors diagnosed that his liver was decomposed and that he would need a liver transplant. Since August 2019, Bharath's life was in a turmoil, with frequent hospital admissions, tapping procedures and hospital bills that cost him a fortune. Being the sole breadwinner of the family, Bharath was terrified of the mounting financial crisis and his deteriorating health condition. He also suffered hypoglycemia around this time.

The estimated cost of a liver transplant was clearly beyond his means and Bharath was at loss as to how to go about it. Fortunately, help poured in from his friends, who started a crowd funding campaign on

Milaap for meeting his transplant costs. Meanwhile, Bharath continued to suffer from fungal and urinary infections. At this point, Bharath's doctors gave him 2 months' time, within which he had to undergo a liver transplant.

He registered himself on the waiting list for a liver transplant and began a painful wait. At a stage in his life, where he had begun to lose all hopes, one of his friends came forward, like an angel, to donate a part of her liver. Even though all the criteria for the donation were met and the donor was a match, he suffered from recurring infections, due to which his transplant had to be delayed and these caused him setbacks – emotionally, financially and mentally.

He was running out of time and he needed the liver transplant immediately. On 30<sup>th</sup> August 2019, Bharath underwent the liver transplantation at Aster Medcity, under Dr. Rajiv Lochan and Dr. Mathew Jacob's team at Cochin. A few months after the transplant, he started noticing great improvements in his health and he began to feel much better. He gradually resumed all normal life activities.

#### It is not over yet – Kidney and Pancreas Transplant

Bharath was grateful that the worst was behind him, and that he could enjoy the pleasures of leading an ordinary and healthy life. Little did he know what lay ahead. Around January 2021, complications relating to type 1 diabetes began bothering him. He developed edema on his legs and his creatinine levels were quite high. After a kidney biopsy, his doctors informed him that the complications were caused by diabetic nephropathy. Dr. Vishwanath S, Nephrologist at Manipal Hospitals, Bengaluru suggested that Bharath would have to undergo a combined kidney and pancreas transplant.

Bharath was tired – tired of fighting. Yet he knew that giving up was not an option. The responsibility of clearing the huge pile-up of loans, taken for his previous treatment, lay squarely on his shoulders and he did not want to burden his parents with it. During this time, his friends were a great source of motivation and gave him a lot of courage to take it as another challenge.

He began researching on the internet and could not find much information about similar cases in India. He decided to undergo the combined kidney-pancreas transplant and registered himself at KIMS



Living with liver failure



# **Invited Article**



After liver transplant

Hospital, Hyderabad as suggested by his doctors. He was determined to fight for life and decided to keep the worries at bay, while keeping himself in positive spirit.

Once again, his friends raised money for him through crowd funding platforms. Meanwhile, Bharath's health continued to experience rough patches with symptoms of vomiting, loss of appetite and fatigue. He had to be provided nutritional supplements through a syringe that ran inside through his stomach, followed by dialysis. "My doctors kept

encouraging me all the time and the prayers of my family and friends kept me going, I suppose", shares Bharath.

Soon, their prayers were answered and Bharath got a call from the KIMS Hospital about getting kidney and pancreas from a deceased donor. He rushed to Hyderabad and after a battery of tests, Bharath was informed that the organs were a match. On December 12, 2021, Bharath underwent kidney and pancreas transplantation under Dr. Ravichand C Siddachari, coordinated by transplant coordinator Mr. Yuvaraj Boopathi. "Each and every time I go to the final stages of death and come back", shared Bharath, ruefully.

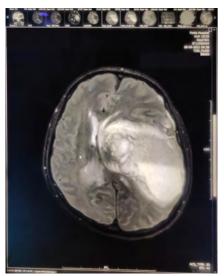
After the initial hitches, post-transplant, his body began to settle gradually. At the time of this interview, a month into his transplant, Bharath is rehabilitating himself into his normal day to day activities.

#### Gratitude

"I have won the battle multiple times and it was not at all easy. I am extremely grateful for these second chances. I can't thank my family, friends, donors and doctors enough, for giving me hope and support when I needed them the most. Without them, I couldn't have done it", said Bharath, with a look of gratitude in his eyes.

## First Report of Domino Liver Transplant from India

Domino liver transplant (DLT) is performed by using the explanted liver of a liver transplant recipient as the donor graft in another patient. This is usually feasible when liver transplant is performed in the initial recipient for hereditary metabolic disorders like familial amyloid neuropathy. The explanted liver, which is structurally normal, is then transplanted into another patient, usually with liver malignancy. The first domino liver transplant was done in India recently, but in very different and unusual circumstances.



Mr ABC (name changed), 53 years, underwent a deceased donor liver transplantation for decompensated cirrhosis of liver due to autoimmune hepatitis at Fortis Memorial Research Institute, Gurugram, in September 2021. The donor, a 44 years old lady, was declared brain dead in the same hospital following brain hemorrhage due to ruptured aneurysm. Mr ABC was doing well post liver transplant with good graft function. Unfortunately, on Day-6

following liver transplant, while still in ICU, he developed sudden loss of consciousness with generalized seizures. MRI brain revealed massive intra-cranial bleeding (fig). Soon he developed signs of brain stem dysfunction in the form of non-reactive pupils and absent cornea and gag reflexes. The first set of tests for brain death, including the

Apnea test, carried out by the brain death committee, were suggestive of irreversible brain stem damage. The family was counseled on the unfortunate turn of events by the liver transplant and ICU teams. Over the following 5 days, the family was repeatedly counseled on the opportunity for organ donation by a team approach. At least three members were always present for the counseling, viz. from medical administration, transplant coordination and one expert by rotation from critical care / neurology / neurosurgery. The family, shocked by the sudden turn of events, took their time to decide on donation. Meanwhile, the critical care team continued the donor maintenance protocol and the second set of tests for confirmation of brain death were done.

On the 5th day of counseling, when the family consented to donation of kidneys and the liver, the donor was not on inotropes, BP 150/90 mm Hg, pulse 80/minute, Hb 7 G/dl, WBC count 25,620/cmm, X-ray chest was normal, blood culture sterile, creatinine 1.02 mg/dl, sodium 145 meq/L, potassium 3.42 meq/L, bilirubin 1.0 mg/dL, AST 49 U/L, ALT 151 U/L. Retrieval of both kidneys and the transplanted liver were done 7 days, 23 hours and 49 minutes after the diagnosis of brain death

The liver was allotted by NOTTO to a hospital in the NCR. This was the first time in the country that a previously transplanted liver was up for allotment. Most prospective recipients from liver transplant centers in the NCR, when offered the liver, expressed uncertainty and concern with likely outcome of using such a liver and opted against transplantation. Fortunately, the team at Max Hospital, Delhi, were able to find a suitable recipient who was willing to accept the previously transplanted liver. The surgery was successful and the recipient did well post operatively and continues to do well at 5 months follow-up.

Dr Avnish Seth, Ms Neha Sharma, Ms Sukhvinder Lal

## My Journey Through and After My Transplant



Mr. Raghavendra Nagaraj

#### Background to my transplant

I was diagnosed with Liver Cirrhosis in March 2010 and informed by the doctors that I would need a liver transplant in about 3 years' time. Things were going fine until June 2014, when I developed appendicitis and was suggested to go for surgery. The surgery got complicated and the liver took a beating. At this point in time, my gastroenterologist recommended me to consult Professor Mohamed Rela.

This was when I first met Professor Mohamed Rela in July 2014. He opined that my liver was still good and if managed well, I could postpone my transplant for the next few years. I was treated by Dr.Rela's colleagues at the Global Hospitals, Chennai. Here again, things were going fine until February 2017 when I got infected and developed swelling in my feet. By then Dr.Rela suggested that this might be the right time to get the transplant done as I was fit to undergo the procedures and the post-transplant recovery would be quick and I could get back to normal activities in three months' time.

Since there was no donor in my family, I had to register myself with the Government of Tamil Nadu and waited for almost 10 months. Those 10 months were the most difficult time in my life. I developed many complications during my waiting period. I was frequently admitted to the hospital for the removal of fluids. I was completely malnourished and lost almost 30 kgs of weight in about eight months' time. On 10<sup>th</sup> October 2017, I was admitted to the hospital with very low blood pressure and swollen abdomen. The next day afternoon, Dr.Dinesh Jothimani, Hepatologist and Liver Transplant Physician told me that he would discharge me as nothing more could be done at that point in time. He said, "I am going to miss you if you do not receive a transplant in a few days' time".

All the stars were aligned for something good to happen on the same day. At 2'O clock in the afternoon the Transplant Coordinator, Mr. Sivakumar visited me and told me that there was an organ available and I should get prepared for my transplant. All the tests were performed and the surgeon explained the transplant

procedure once again, the risks and complications involved in the surgery, and the pros/cons. It was 12<sup>th</sup> October 2017, the day I received my transplant and after a 12-hour surgical procedure, I was moved to the ICU. After 16 days, I cleared all the check boxes and was ready for discharge. I would say 'It was a new lease of life'.

# Staying healthy and fit after transplant and participating in the World Transplant Games

Starting from the time I was diagnosed with Liver Cirrhosis till my successful transplant, I realised that there was a complete ecosystem, involving hospitals, nurses, doctors, family, friends, relatives and employers, who work with us to get us back on track hale and healthy.

I have to say that the above ecosystem will collapse without the ultimate sacrifice of the donor family who comes forward to donate the organs of their loved ones.

After having undergone a Deceased Donor Liver transplant, I wanted to be very responsible and ensure that the hard work of so many people should not get wasted. I decided to work towards keeping myself fit and healthy.

Post my transplant, I was regularly visiting the clinic for check-up. Three months after transplant, my scars from the surgery reduced significantly and I had no pain whatsoever. I was doing simple walking exercise in my house for about 5km daily. I even returned to my work five month after my surgery and continued to do walking and simple stretches regularly.

During one of my regular clinic visits in May 2018, I was sharing with Dr.Dinesh about my routine fitness practices. Immediately Dr.Dinesh told that I should train well and participate in the World transplant games (WTG). He shared the website details and asked





Mr. Raghavendra Nagaraj at World Transplant Games, New Castle, UK – 2019

# Recipient Story

me to go through the information and contact the right people. I got very excited and spent a lot of time understanding the games by going through their website. I decided to participate in the 2019 WTG held in New Castle, UK.

I trained myself very hard for more than a year. I built a home Gym with good equipment and trained under the supervision of a good trainer. By the latter half of 2018, I was running half Marathon to build a good muscle strength. This gave me a huge confidence to participate in the WTG 2019.

Participating in the WTG was a wonderful experience which had 2000 transplant recipients across the world. It gave me an opportunity to interact with people who have undergone various organ transplants such as liver, kidney, heart, bone marrow transplant, etc. It was highly encouraging to meet people who were leading a healthy life after 20 years of transplant. From India, a team of 17 members participated in the games and won many medals on different categories. It was a very confidence building experience for someone like me who was staring at death a year back!

In fact, I am preparing myself for the next World Transplant Games to be held in Perth, Australia in 2023.

# Addressing physical and psychological well-being during COVID-19

COVID-19 was one of toughest times for all of us, especially for the transplant recipients. Since we are on immunosuppressive medications, we are easily susceptible for any infections. It was becoming more challenging for the doctors and hospitals to monitor transplant recipients. Also, doing transplants seemed not possible at least in the initial phase of the pandemic as the hospitals were over burdened with COVID patients.

Moreover, due to the lockdowns people could not go out for their regular exercises to keep them fit. This was again not helpful not only to the transplant recipients but also the ones who were waiting to undergo a transplant.

I was fortunate that I could construct my own home gym where I could exercise regularly and keep myself fit. Honestly, lockdown helped me improve on my fitness levels and keep COVID out of my way.

#### My message to the transplant recipients out there

- Take your medicines regularly. DO NOT STOP IMMUNOSUPPRESSANTS. Many people after getting better, stop their medications on their own and end-up in rejection of transplanted organ.
- Visit your doctor / clinic as per the schedule. Do not miss your tests



Workout at home

- Exercise regularly. Like walking, simple stretching, running, cycling, swimming and weight training. Understand your body and do this to the level that your body can handle. Do not overdo. Avoid contact sports like football, hockey and basketball.
- Transplant recipients can live a normal and long life if we really
  value the efforts made by so many people who have helped us
  to live by following those simple steps.

Personally, I must tell that I am having a very happy, healthy and satisfying life after transplant. In February 2022, my services got extended by 2 years after my retirement. Not only that, I also got promoted as the President (North) of my company. All these happened because the company felt that I was healthy and I could contribute more to the organisation.

My transplant journey and my mental and physical well-being after transplant have embarked enormous confidence to explore new things in my life.

## Making Transplants Affordable – An initiative by MOHAN Foundation

Anudaan – Making Transplants Affordable has been committed to making life saving organ transplantation accessible to all those who need it in India. This initiative aims to enable and support financial assistance for organ transplantation for economically disadvantaged patients through crowd funding. One becomes eligible for help under the Anudaan initiative for a 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.

### Organ Transplants Supported by Anudaan



Baby Deeksha PS, 7 years, Davanagere, Karnataka.

Underwent liver transplant on October19, 2021 at Aster CMI Hospital, Bengaluru.

Anudaan contributed Rs. 2.5 lakh and worked with the hospital to bring down the transplant cost.

"Lots of gratitude to MOHAN Foundation's Anudaan team for saving our daughter's life with their financial support. We are impressed by their good and lifesaving work." – Mr. Prasanna Kumar P, Father

> Master Kabyaneel Parashar, 9 months, Darrand, Assam.

> > Underwent liver transplant on September 24, 2021 at Max Super Specialty Hospital, Saket, New Delhi.

#### Anudaan contributed Rs. 2 lakh.

"Thank you so much for saving my child's life with your financial support" – Mrs. Sumi Kalita, Mother

"I want to express my gratitude towards MOHAN Foundation for offering financial aid for my son's transplant. Please keep up the lifesaving work that you are doing" – Mr. Mridul Kalita, Father



Master Addwikh Tejj, 5 years 8 m o n t h s , Muthyalanagar, Bengaluru.

Underwent liver transplant on December 24, 2021 at Manipal Hospitals, Bengaluru.

A n u d a a n c o n t r i b u t e d Rs. 1.5 lakh and worked with the hospital to bring down the transplant cost.

"I will be greatful to MOHAN Foundation for lifelong as they have saved my son's life with their generous support." – V. Lavanya, Mother

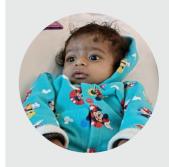


Mr. Ganesh Ghorpade, 35 years 5 months, Pune, Maharashtra.

Underwent kidney transplant on February 12, 2022 at Sahyadri Super Speciality Hospital, Pune.

#### Anudaan contributed Rs. 2 Lakh.

"I would like to thank MOHAN Foundation's Anudaan team for their financial support for my husband's kidney transplant. I am so happy to see him slowly resuming a normal life." – Monali Ghorpade, Wife



Master Devyansh Dev, 6 months, Madhubani, Bihar.

Underwent liver transplant on December 31, 2021 at Max Super Specialty Hospital, Saket, New Delhi.

# Anudaan contributed Rs. 3 lakh.

"We are extremely grateful to MOHAN Foundation's Anudaan team for all their support." – Jyoti Gupta, Mother

"Thank you so much MOHAN Foundation for supporting our son's liver transplant. May your Foundation continuous to grow and keep helping underpriviledged people like us." — Rajiv Prasad Gupta, Father



Master Aryan Kumar, 6 months, Shahbad Dairy, North West Delhi.

Underwent liver transplant on September 29, 2021 at Max Super Specialty Hospital, Saket, New Delhi.

Anudaan contributed Rs. 2.5 lakh.

"Aryan is my first child and he is so special. Thank you MOHAN Foundation's Anudaan team for supporting my child's liver transplant and saving his life" – Pinki Kumar, Mother

"I am very happy now to see my child free from suffering and pain. When my health condition would improve with God's grace, I would like to donate fund to MOHAN Foundation to support their lifesaving and noble work" – Devender Kumar, Father

Master Naitik Chugwani, 9 years, Udaipur, Rajasthan.

Underwent liver transplant on February 10, 2022 at Max Super Specialty Hospital, Saket, New Delhi.



Anudgan contributed Rs. 2 Lakh.

"Lots of gratitude to MOHAN Foundation's Anudaan for supporting my son's liver transplant. He has received a gift of life." – Dheeraj Chugwani, Father

# Corneal Transplants by Anudaan With support from Century Plyboards India Limited

Mr. Kashi Nath,
70 years, Deoria,
Uttar Pradesh.

Underwent corneal
transplant on

November 6, 2021 at Ahooja Eye & Dental Institute (AEDI),

Gurugram, Haryana.

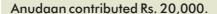
#### Anudaan contributed Rs. 20,000.

'Thank you so much MOHAN Foundation for supporting my corneal transplant and changing my life forever.' – Mr. Kashi Nath Dixit

'I have no words to express my joy and gratitude. With support of MOHAN Foundation, my father underwent corneal transplant. I want to congratulate the Foundation for their life-saving work. May the Foundation continue its extraordinary work and supporting underprivileged people like us.' — Sailesh Dixit, Son of Mr. Kashi Nath

Mrs. Rukman Ahirwar, 70 y e a r s , Chattarpur, M a d h y a Pradesh.

Underwent corneal transplant on November 2, 2021 at Ahooja Eye & Dental Institute (AEDI), Gurugram, Haryana.



"I am thankful to MOHAN Foundation for supporting my corneal transplant and giving me a gift of sight." – Mrs. Rukman Ahirwar

"Thank you MOHAN Foundation for all your support. It is great to now see my mother out of pain and suffering." — Satya Prakash Ahirwar, Son



Mr. Kalu Nath, 56 years, Ujjain, Madhya Pradesh.

Underwent corneal transplant on January 10, 2022 at Ahooja Eye & Dental Institute (AEDI), Gurugram, Haryana.

#### Anudaan contributed Rs. 20,000.

'I would like to thank MOHAN Foundation for supporting my corneal transplant and giving me the gift of sight.' – Mr.Kalu Nath



Century Plyboards India Limited decided to undertake the cause of organ and corneal donation in collaboration with MOHAN Foundation. They have contributed towards 'Anudaan – Making Transplants Affordable' to support corneal transplants of underprivileged patients, thereby giving them the gift of sight. They also created a motivational film on corneal donation.

https://www.mohanfoundation.org/anudaan.asp



# **Training Programme**

## **One-month Online Transplant Coordination Professional Certificate Course**



Mrs. Lalitha Raghuram addressing the participants on Basic Concepts of Organ Donation and Transplantation – November 2021



Ms. Trilly Rachel Mathew briefing the list of documents required for living donation – December 2021

The one-month online 'Transplant Coordination Professional Certificate' course was successfully conducted in the months of November 2021, December 2021 and February 2022. The participants were from all across India as well as from Nepal. As part of the course, webinars were conducted through the Zoom platform where participants were given the opportunity to interact with experienced transplant coordinators across the country. A total of 111 candidates completed the course in these three batches and received their certificates.



Mr. Haider Ali Khan talkiing on Transplant Coordinators' Role in a living donor transplant programme – February 2022

## Post Graduate Diploma in Transplant Coordination and Grief Counselling – 2021 Batch



Healthcare Management & Communication by Dr. Suryakumari, Founder and President, The Academy of Life and People Skills, Chennai



Stages of grief explained by Ms. Bhavana Shah, Sr. Executive — Administration & Transplant Coordinator, Wockhardt Hospitals, Mumbai



Mr. Naveen Nandigam discussing the five pillars of leadership

The 2021 batch of the one-year online 'Post Graduate Diploma in Transplant Coordination and Grief Counselling' successfully completed their course in December 2021. A total of 34 participants from diverse professions from India and Botswana completed the course.

As part of the course, contact sessions were conducted virtually using the Zoom platform. The sessions focused on the counselling process, approaching grieving families for organ donation, soft skills for transplant coordinators, communication skills in healthcare management, resolving conflict and stress-proof oneself, transplant law in India, the role of a transplant coordinator in the deceased donation and living donor transplant coordination. The webinars also involved activities like quizzes and discussions that kept the participants engaged in the learning process.

# Training Programme

The faculty for the webinars included

- Mr. K. Veerapandian (Consultant Psychologist and Assistant Professor of Psychology, Banyan Academy of Leadership in Mental Health, Chennai)
- Dr. Suryakumari (Founder and President, The Academy of Life and People Skills, Chennai)
- Mr. Naveen Nandigam (CEO, 3N Training, Hyderabad)
- Mr. Sivakumar (Assistant General Manager Liver Transplant Unit, Dr. Rela Institute & Medical Centre, Chennai)
- Ms. Bhavana Shah (Sr. Executive Administration & Transplant Coordinator, Wockhardt Hospitals, Mumbai).

#### **Feedback**

**Lt. Col. Meenakshi Devi Sharma**, Army Institute of Cardio-Thoracic Sciences (AICTS), Pune



I Lt. Col. Meenakshi Devi Sharma was part of PGDTC & Grief Counselling 2021 and with immense pleasure I am writing this

feedback post completion of the course dated  $25^{\text{th}}$  December 2021. Please treat this as my gratitude towards the hard work team has done in order to impart the required knowledge.

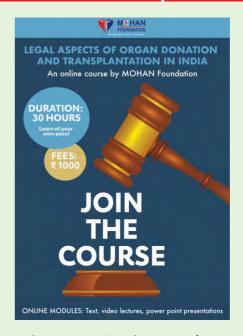
Over all the course has imparted new knowledge to me and hopefully it will help me in my professional career. The course is well structured and coordinated well; it helped me to gain the required knowledge with ease. I'm feeling confident gaining the knowledge and would like to explore more professional opportunities in the area.

# Online Course on Family Counselling and Conversations on Organ Donation



A 15-hour online course "Family counselling and conversations on organ donation" was introduced by MOHAN Foundation in December 2021. This course helps the learners not only to understand emotionally intensive conversations with grieving families but also equips them to offer the option of organ donation with sensitivity and empathy. The online modules include simulations of family conversations and case studies.

# Online Course on Legal Aspects of Organ Donation and Transplantation



A 30-hour online course, "Legal aspects of organ donation and transplantation" was launched by MOHAN Foundation on January 6, 2022. This course was developed with an educational grant from Trans Asia Consultants Pvt Ltd. The course aims to benefit the medical, paramedical and administrative personnel in hospitals and help them gain knowledge about the legal aspects of organ donation and transplantation in India. The course was launched by Dr. Vikas Mahatme, Member of Rajya Sabha & Founder Medical Director of Mahatme Eye Bank Eye Hospital, Nagpur. Also present was Dr. Rajneesh Sahai, Director, National Organ & Tissue Transplant Organization (NOTTO). As part of the launch, a panel discussion on "Critique of the Act-25 years later" was organized. Various experts were invited to revisit the Act and critique it to better understand gaps and future recommendations.



Inaugural address by Padma Shree, Dr. Vikas Mahatme Member of Rajya Sabha

## A Project to Arrange MoU for All Commonwealth Countries, A Project Like No Other!



Dr Satya Sharma, MBE, DL Chair, Tribute to Life Board

#### Introduction

The Commonwealth Tribute to Life project was initiated in 2018.

The Birmingham 2022 Commonwealth (CW) Games present a unique opportunity to showcase organ and tissue donation and transplantation. We have sought the support of all Commonwealth nations to join this noble and humanitarian effort to save lives.

Through the sharing of knowledge and expertise we will increase ethical organ and tissue donation and transplantation, regardless of transplant infrastructure, for the benefit of all Commonwealth citizens. We would empower health professionals to achieve a step towards equality for 2.3 billion citizens of CW countries, approximately one third of the world population.

The World Health Organisation's Global Observatory on Donation and Transplantation estimates that there were over 146,000 organs transplanted in 2018. This gift of life came from the generosity of over 40,000 living donors (most commonly through the donation of a kidney) and from nearly 39,000 deceased organ donors. Yet organ failure and the need for transplantation remains high in all nations.

The rate of donation varies from zero donors in some Commonwealth Nations to over 20 per million population in countries like Australia, Canada, Malta and the UK. We face common challenges to increase rates of donation across all social groups, ethnicities and religions.

Such unmet need can lead to the death of those on the transplant waiting list or commercially driven transplantation to the detriment of both organ donors and recipients. The Declaration of Istanbul and the resolutions of the World Health Organisation's Guiding Principles on Organ Transplantation call on every nation to strive toward self-sufficiency in clinically safe and ethically sound organ and tissue donation and transplantation. No nation has yet to achieve this ambition of self-sufficiency.

#### What we are promoting

- 1. The value of organ and tissue donation and transplantation in saving and transforming lives
- 2. The need to ensure safe and ethical practice in accordance with the Declaration of Istanbul and the resolutions of the World Health Organisation's Guiding Principles on Organ Transplantation
- 3. The benefits that can be shared by all Commonwealth nations through learning and sharing solutions with each other about the common challenges we face

Using the historical ties and established relationships of our Commonwealth Citizens and governments, we believe more can be done through Commonwealth Nations working together to share knowledge and expertise.

#### Structure

NHS Blood and transplant (NHSBT) is part of NHS UK. NHSBT created a board for Tribute to life. The board has two advisory panels, UK Advisory panel to connect the board with parliamentarians and other key stakeholders within UK to achieve the objectives, chaired by Baroness Finlay. International Advisory Panel (IAP) has members for each CW nation to carry out the functions, chaired by Dr Dale Gardiner. It would be expected that IAP member would create an implementation group within the



Dr Dale Gardiner, UK Chair, International Advisory Panel

country to include a team of enthusiastic professionals to carry out the aims.

There are six regional co-ordinators, currently Dr Dale Gardiner, (Europe), Dr Sunil Shroff (Asia), Ms Lucinda Barry (Oceania), Dr Maragret O'Shea (Caribbean), Dr David Thomson (Africa), Catherine Butler (Americas).

#### **Achievements**

From Antigua to Zambia, with support from nations in Africa, Asia, the Americas, Europe and the Pacific, at the time of writing 41 (76%) nations have supported the project. This covers the 98.6% population of the commonwealth nations. The disconnect between percentage of countries and the population is due to the fact that some small countries which have a population of less than half a million are not connected, these may never be able to create transplantation facilities. Some countries in African continent feel that the limited resources should be directed towards other priorities such as combating starvation or coping with natural calamities such as earthquakes and floods. We understand these difficulties but know that xenotransplantation, if successful could be a game changer. Equally, life of each citizen has same value and wherever possible, should be saved. All Governments should be honour bound to save the life of every citizen.

We have debated the Memorandum of Understanding (MoU) with all 41 representatives and this has been agreed, available through the link on the webpage; https://www.odt.nhs.uk/odt-structures-and-standards/clinical-leadership/commonwealth-tribute-to-life-project/

The MoU is for five years, renewable after the term, financially neutral and not legally enforceable but provides a template for cooperation in this complex field. The MoU would also not promote transportation of organs across counties which can cause difficulties. However, it will allow members to communicate with each other without any restrictions to encourage best practice.

#### **Action Plan**

The project will be launched on the Commonwealth Day on 14<sup>th</sup> March 2022 in Wolverhampton, UK. We wish to monitor progress made annually thereafter through the board. The project will have inaugural celebration on 22.7.22, a week before CW games to inform the general public and wider audiences within CW nations.

We hope that creation of this platform will allow participants to use it fully to derive benefits through health professionals to reach the citizens. The success of project will be through the creation of implementation groups and active participation of nations as well as enthusiasm of IAP members.



### MOHAN Foundation's Expertise Sought in the UAE's Ogan Donation Programme



Ms Pallavi Kumar discussing how MOHAN Foundation could help the UAE organ donation program



Ms Pallavi Kumar being felicitated by Dr. Mariam Al Mazrouei, Executive Director, Haealthcare Payers Sector, Dept of Health



Delegates from other countries

Ms. Pallavi Kumar, Executive Director (NCR), MOHAN Foundation was invited to Abu Dhabi by the UAE Organ Donation and Transplant Committee, headed by Dr. Ali Al Obaidli, from November 22-25, 2021.

As UAE celebrates its 50<sup>th</sup> National Day and takes a focused look at its organ donation program. Home to over 200 nationalities, Indians constituting 38% of the total population, they are keen to work with other countries where these expatriates come from to understand each community better.

Visits to transplant centres and engaging discussions with the MoHAP (Ministry of Health and Prevention) and other private and public stakeholders marked the 4-day visit to discuss collaboration and knowledge exchange. Other delegates from Pakistan, Bangladesh, Nepal, Kuwait, Jordan, and US too were part of these discussions.

#### SABERA Lifetime Achievement Award 2021



Dr. Sunil Shroff, Managing Trustee, MOHAN Foundation has been awarded the SABERA Lifetime Achievement Award 2021 for his pioneering work in the field of organ donation. The same was announced at SABERA grand virtual summit on December 9, 2021.

SABERA (Social and Business Enterprise Responsible) Awards, endeavors to acknowledge Purpose beyond Profit. It was launched by the UN Women awardee Simply Suparnaa. SABERA aims to be the tripartite bridge between the three sectors of corporate India, civil and non-profit sectors. A wide spectrum of entries were received for the award from India's largest businesses, impactful nonprofits and passionate individuals.

# Celebration of Life – A Virtual Concert by Padma Shri Usha Uthup in aid of Organ Donation



MOHAN USA, organised a virtual concert on the evening of  $31^{\rm st}$  December 2021 (6 pm PST and 9 pm EST) by Padma Shri Usha Uthup to support the cause of organ donation and the work undertaken by MOHAN Foundation.

Smt. Usha Uthup enthralled the audience with a variety of songs in different languages and also spoke about organ donation and appealed to the audience to pledge to donate organs and save as many lives as possible. The concert was streamed live on MOHAN Foundation's YouTube and Facebook. There were 534 views on YouTube and 376 views on Facebook.

This event was held in partnership with Indian Fine Arts Academy of San Diego (IFAASD) and MOHAN Foundation – Jaipur Citizen Forum (MFJCF). We thank all our financial donors for their generosity. This generosity comes as a shot in the arm for our life saving work.

# **POST GRADUATE DIPLOMA IN** TRANSPLANT COORDINATION & GRIEF COUNSELLING

CREATING A CADRE OF HEALTH CARE PROFESSIONALS DEDICATED TO "TRANSPLANT COORDINATION AND GRIEF COUNSELLING" IN INDIA AND ASIA TO IMPROVE ORGAN DONATION RATE IN THIS REGION.

## Unique, First of its kind in South Asia

## el.mohanfoundation.org

- A structured one-year course blended learning experience
- For Doctors, Nurses, Allied Science graduates, Graduates in any subject, Masters in Social work, Psychology, Social Sciences, Public Health, Hospital Administration, Sociology
- 70 modules covering medical, legal, ethical and religious aspects, counselling, grief counselling and transplant coordination









MS. SANGITA SEDHAI, NEPAL (2019 - 2020 Batch) Transplant Coordinator - Renal Transplant Unit Grande International Hospital, Kathmandu

I have been working as a transplant coordinator since 2016 without any structured training. This course has helped me in various ways - it not only introduced me to the basics of brain stem death and organ donation, but it also gave me insights into grief counselling, its stages, ethical aspects and organ allocation & sharing. The course comprehensively covered clinical and legal aspects. The case studies provide a framework to understand and manage the realities. Engagement throughout the course through assignments, project work and assessments, contact sessions with experts and sharing of experiences sets this course apart. I suggest all to take this course if they wish to be a good transplant coordinator.



MS. NEHA SHARMA, INDIA (2021 Batch) Senior Assistant - General Administration Fortis Memorial Research Institute, Gurugram

A good education is the foundation for a better future. MOHAN Foundation has thus helped me grow. I joined the one-year online transplant coordinators' course during COVID times and I was very eager to learn more on the transplant process. I learned about the medical as well as legal aspects of transplant process - this provides a clear structure to comprehend and handle the ground situation. I was blessed to be taught by the faculty of MOHAN Foundation, who are entirely devoted to imparting best knowledge. The course gave me a new direction in life and helped me choose a profession through which I can not only help many, but also have a fulfilling career.



TESTIMONIAL DR. MATHEW JACOB

Senior Consultant Hepato Pancreato Biliary & Abdominal Multi Organ Transplant Aster Medcity Kochi

I am happy to know that Mr. Mathew Joseph Sabu is a successful candidate of the Post graduate diploma in Transplant coordination and grief counselling, November 2020 batch. This course has helped him develop his skills and knowledge to practice as a Transplant coordinator. This is reflected in his daily performance.

I appreciate the efforts by the team for developing such an excellent curriculum. The efforts by MOHAN Foundation to train transplant coordinators are remarkable.

# **ACROSS INDIA, SOUTH ASIA & BEYOND**



# 92 CANDIDATES TRAINED

(2017 - 2021)

**INDIA - 81** 

VIETNAM - 1

PAKISTAN - 6

SPAIN - 1

NEPAL - 1

**BOTSWANA - 1** 

QATAR - 1