ANNUAL REPORT April 2009 to March 2010

INTRODUCTION

January 12, 1997- the day MOHAN Foundation started on its journey to give patients with organ failure a second lease of life. Organ donation and transplantation has made it possible for people with organ failure to look forward to a brighter tomorrow filled with hope and promise. But, it is up to us to help fulfill that promise by pledging our organs for donation. The majority of patients with organ failure are young and their only hope of living is to have an organ transplant, however, a shortage of donated organs dashes the hopes of many young people.

ABOUT MOHAN FOUNDATION

MOHAN is an acronym for Multi Organ Harvesting Aid Network and was established in 1997. It is a registered Not-for-Profit organization with both 50 and 100% Tax exemption under Section 80G and 35 AC respectively. It is also entitled to receive foreign aid as per the FCRA Act. MOHAN FOUNDATION is the brainchild of a group of highly motivated, concerned and noncommercial group of practicing medical professionals and their well-meaning friends to promote the cause of "Organ Donation".

It was formed to be a facilitator of deceased organ donation and transplant programme in India and has advocated and facilitated various issues in this field. To achieve this objective, it works as a "Support Group for Patients, Physicians & Public". The following have been the objectives of MOHAN Foundation –

- •Creating public awareness among a cross section of population
- •Motivating families of "brain dead patients to donate organs
- •Training professionals (Transplant Coordinators) in facilitating organ donation
- •Liaising with government to pass favorable legislation
- •Networking with other organ procuring organizations in the country
- •Raising resources to promote organ donation efficiently

MOHAN Foundation comprises five core groups that carry out different activities of the foundation. These groups are:

- 1. Indian Network for Organ Sharing (INOS)
- 2. Public education campaign
- 3. Patient Support group
- 4. Publications Indian Transplant Newsletter and Life...Pass it On newsletter.
- 5. Transplant Coordinators' Training Programme

1. INOS (INDIAN NETWORK FOR ORGAN SHARING)

"Let no organ be wasted" is the mission statement of INOS. The group was formed first in Tamil Nadu in January 2000 with Apollo Hospitals, Sri Ramachandra Hospital, Sundaram Medical Foundation, Madras Medical Mission Hospital (all from Chennai), Christian Medical College Hospital, Vellore. It successfully established the fact that organ sharing was the way forward for the deceased organ transplantation programme.

In Andhra Pradesh, the hospitals that have benefited from our work are Nizam's Institute of Medical Sciences, Global Hospitals, Care Hospitals, Medwin Hospitals, Mediciti Hospitals, Kamineni Hospitals, Osmania Hospitals, Krishna Institute of Medical Sciences, Star Hospitals and Innova Hospitals.

The experience gained in INOS in setting up a web-based recipient waiting list registry has been shared with the government run Tamil Nadu Organ Sharing Network. MOHAN Foundation is on the Advisory Committee of the Cadaver Transplant Programme in the state.

2. PUBLIC EDUCATION CAMPAIGN

The Foundation regularly organizes awareness events to a cross section of population. Over 1 million donor cards have been distributed in English, Tamil, Telugu, Marathi and Hindi. The Foundation also has literature on organ donation and prevention of different diseases (almost numbering 100).

Activity Highlights

- "Rally For Life" A Bikethon For Organ Donation In Tamil Nadu
- "Giving Organ Donation A Hand" Programme at Madras School of Social Work
- Taking The Message Of Organ Donation To The Smaller Towns Of Tamil Nadu
- Organ Donation Awareness At Avvai Tamil Sangam, Noida
- Donor Families Honoured on World Kidney Day
- Mr. & Mrs. K. Raghuram Receive ''Real Heroes'' Award Instituted By CNN-IBN

Rally For Life – A Bikethon For Organ Donation In Tamil Nadu



"Rally for Life" - the motorbike rally, organised by MOHAN Foundation, to promote organ donation awareness was flagged off on 09.09.09 at 09:09:09 am by Thiru T. Rajendran IPS, Commissioner of Police, from Loyola College, Chennai. The day was unique and so was the theme - ONE organ donor can save NINE lives.

The reason for undertaking this rally was the spurt in organ donation activity in the state from October 2008 - 109 organs from 36 deceased donors over a period of nine months. MOHAN Foundation felt that this was the right time, literally, to take home the organ donation message to as many places in Tamil Nadu as possible. The six rally members, young men in their 20s working in different corporates have been friends since school. They wanted to make a difference to society through their humanitarian work and expressed their willingness to undertake the 2000 km rally on their motorbikes. The rally covered nine major locations in Tamil Nadu – Vellore, Salem, Coimbatore, Madurai, Tirunelveli, Dindigul, Trichy, Thanjavur – and Pondicherry. At each of these locations, a function was held to felicitate organ donor families in that area as they are the true ambassadors of the deceased organ donation programme. In addition, organ donation awareness talks were also held. The enthusiasm and the meticulous organisation by the hosts (doctors and hospitals) in each of the locations ensured that the rally went through in a seamless fashion.

The closing ceremony of "Rally for Life" was held on 20th September 2009, but it marked the beginning of another campaign - a campaign to include the 'clause of organ donation on the driving license.'

With 80,000 deaths on the road and almost 40,000 of them being brain death annually, this simple inclusion on the driving license has the power to save many lives and wipe away the shortage of organs. The special guests of the day were Mr. Syed Munir Hoda, IAS, Additional Chief Secretary, Govt. of Tamil Nadu, Mr. S. Machendranathan, IAS, Transport Commissioner and popular actor/director and social activist, Ms. Revathy Menon. The highlight of the event was that 2500 signatures were handed over by Ms. Revathy Menon to Mr. Machendranathan supporting a request to incorporate an organ donation clause in the driving license.

The "Rally for Life" marked the coming together of doctors, hospitals, NGOs, corporates, and individuals from different walks of life to endorse a gift that is priceless and invaluable – the gift of life.



"Giving Organ Donation a Hand" - Programme at Madras School of Social Work

MOHAN Foundation in collaboration with the Madras School of Social Work participated in a series of organ donation awareness initiatives in October 2009. Organ donation awareness talks were held at Dharmamurthi Rao Bahadur Calavala Cunnan Chetty Hindu College, Avadi and the Madras School of Social Work. An awareness drive was also held at the Marina beach. In addition, there were poster, mime and street play competitions with the theme of "organ donation." Students from different colleges used the opportunity to convey the message of organ donation in many innovative ways. Mr. Charu Haasan, eminent actor, who was the Chief Guest on the final day spoke about his brother, the famous actor, Mr. Kamal Haasan, had pledged to donate his body to medical science.

Taking The Message Of Organ Donation To The Smaller Towns of Tamil Nadu

Tamilnadu Parkkavagula Moopanar (Surthimar) Sangam celebrated its silver jubilee on 30th December 2009. A grand function was organised at Thiruvaiyaru (15 kms from Thanjavur in Tamil Nadu) to popularise the concept of organ donation in the community.

On this special occasion, MOHAN Foundation staff from Chennai made a presentation on organ donation. Dr. Senthilnayagam, consultant nephrologist from Thanjavur, explained the concept of brain stem death and cadaver organ donation. Dr.Shanmugam spoke about blood donation and Mr.Vasantha Kumar about eye donation. He also expressed his gratitude to all the people of a remote village in Tamil Nadu where the community ensures that the eyes of anyone who passes away in the village is donated.

MOHAN Foundation distributed over 500 Organ Donor cards at the function. The Moopanar Sangam members decided to spread the message of "GIVE LIFE.... SAVE LIFE" at every meeting that they conducted in the future. This would give a big boost to organ donation in the state of Tamil Nadu.



Organ Donation Awareness at Avvai Tamil Sangam, Noida

Avvai Tamil Sangam in association with MOHAN Foundation, has organised a four day event to promote organ donation in Noida, UP. Over al lakh people are expected to attend this function and this event is going to go a long way in promoting organ donation.

Avvai Tamil Sangam a social and cultural organisation is a group of creative people. Motto of the organisation is about promotion of Indian Art and Culture and spread out positive message to the younger generation on promoting and respecting India's rich culture.

Formed in the year 2003, had successfully done different programs to promote the culture of India. Avvai Tamil Sangam works towards acting as a true representation of Tamilnadu in Northern states and to exhibit the culture of Tamil Nadu to people of own and other culture.



Donor Families Honoured On World Kidney Day

MOHAN Foundation, celebrated World Kidney Day on March 11, 2010 at Loyola College premises. Incidentally, MOHAN Foundation had installed a plaque in memory of the organ donors of chennai 10 years ago and also planted saplings at the same place, many of which have now grown to tall trees!

It was but fitting that we celebrated the world kidney day here, by inviting some Donor families and recognizing their support to the cause of Organ Donation.

First of all, Dr Sunil Shroff gave a short talk. Then, Transplant Coordinator Veena read out a poem on Organ Donation. This was followed by a moving poem rendering by Dr Sumana written by a mother who had lost her young son in an accident but had donated his heart.

Then, all the donor family members laid a wreath and a garland at the plaque.

Mr Anant Krishnan, Internet editor of The Hindu, gave away a certificate to each of the donor families, honoring their selfless act of donating organs and saving lives, at a time of terrible grief of losing their loved ones.

Thanks to the donor families who had kindly attended the function and also to all the Donors all over India who are such a pillar of support to the Organ Donation campaign!

Mr. & Mrs. K. Raghuram Receive ''Real Heroes'' Award Instituted By CNN-IBN



March 5, 2009 was a day of celebration for MOHAN Foundation when Mr. & Mrs. K. Raghuram, Directors, MOHAN Foundation, Hyderabad received the REAL HEROES award instituted by CNN-IBN. Mr Yash Chopra, film director handed over the Real Heroes trophy and a cheque of Rs.5 lakhs to them. This was in recognition of the fact that the Raghurams actually "walked the talk" when they donated their son's organs when he passed away. Their son, Swaminarayan (19), met with a tragic car accident on 13 January 2004 in Hyderabad and was

declared brain dead. The grieving but courageous family donated his organs and gave five people a new lease of life. By bestowing the Real Heroes award on the Raghurams their supreme gesture of altruism was given the recognition it deserves. The Raghurams thanked CNN-IBN and Mrs. Nita Ambani, Reliance group, for their support.

List of Public Education Programmes:

Indira Group of Institutions SRISHTI 2K9- Together We Can TIDC SSN College Merrill Lynch Ride-A-Thon on Organ Donation awareness by HCL Tech MOP Vaishnav College Accenture Servion Global Solutions Naraiwan Controls India Pvt. Ltd., SIP Academy at Chennai Trade Centre Honouring Organ Donor Families at Hyderabad



3. PATIENT SUPPORT GROUP (PSG)

MOHAN Foundation started a Patient Support Group (PSG) for organ failure patients and their families to give them a platform to discuss their problems with each other and also interact with a panel of experts comprising doctors, dietitians, and counselors. There are about 300 members in the group. The PSG is also working towards becoming a strong advocacy group so that organ failure patients can lobby for change and have a common platform from where their grievances can be heard. Subsidized transplant related medicines to needy patients are supplied

4. PUBLICATIONS

- <u>a.</u> <u>Indian Transplant Newsletter (ITN)</u> The Indian Transplant Newsletter is being published since 1998 and is currently in its 28th issue. It carries national and international transplant news and keeps track of the Indian cadaver(deceased donor) transplant programme. The executive committee has doctors from the transplant field from all over the country and abroad. About 1500 to 2000 copies of the newsletter are dispatched every quarter to transplant clinicians and members of the public in India and abroad.
- <u>b.</u> <u>Life...Pass it On Newsletter</u>- A recent publication of the foundation covering the heartrending stories of organ donor families.

5. Transplant Coordinators' Training Programme

One Month Training Programme – December 2009, Chennai

The success of an organ donation and transplant programme depends on good coordination and trained transplant coordinators and trained transplant coordinators are the key.

MOHAN Foundation conducted the first full-fledged one-month induction course "Transplant Coordinators' Training Programmes". The programme involveed training social workers, medical and paramedical staff in counselling families of 'brain dead' patients to donate organs and coordinating the entire process of organ donation, retrieval and transplantation. They were trained in all aspects of counselling with intense one-on-one role play by very experienced transplant coordinators drawn from across the country. This strengthened the trainees' abilities to go back and counsel the families of "brain dead" patients independently. In addition to counselling, they were learnt the importance of working within narrow time-frames and linking with recipient hospitals, the forensic department and the police (in medico-legal cases) to ensure that organs are retrieved optimally and the body handed over to the family with respect and on time.

The 12 transplant coordinators who were trained came from diverse work milieus – the government health sector, the corporate health sector and NGOs – but the response was extremely positive and enthusiastic. Experts from various fields of organ donation and transplantation were part of the faculty and the participants had a chance to debate, discuss and clarify various issues with them.

At the end of the course, every participant was in a position to create a roadmap for initiating the organ donation programme in his or her hospital/city/region and work as the key resource person to spearhead transplant-related activities. The course also succeeded in creating a strong network amongst the coordinators, which will help take the organ donation movement forward as a whole.



One Week Training Programme- March 2010, Hyderabad:

The first one week Transplant Coordinators' Training Program held at Hyderabad from 1^{st} March – 6^{th} March 2010. 36 candidates participated in the training program. In that 28 were critical care nurses, 3 were social workers and 5 were students of P.G. Diploma of Health Administration. As part of the training program, there were lectures by external and internal faculty, Role Play, Case study discussions, visit to a donor family, dialysis center visit, and a public awareness presentation were undertaken. The candidates were each asked to do a project. (enclosed)





Mohan Foundation's Transplant Coordinators Placed in Government General Hospital, Chennai

MOHAN Foundation signed an MoU in February 2010 with the Government General Hospital, Chennai to place its transplant coordinators there. Their presence has made a tremendous difference to the deceased organ donation programme in the hospital. In a month period (February 2010 to March 2010), 6 deceased multi organ donations took place in the hospital which translated into 11 kidneys, 6 Liver, 1 Heart, 6 Heart Valves and 10 corneas. The overall result was that 34 life-saving organs and tissues were donated.

MOHAN FOUNDATION

FINANCIAL HIGHLIGHTS FOR THE PERIOD APRIL 2009 TO MARCH 2010

INCOME

2008-2009 Amount In INR	Particulars	2009-2010 Amount In INR
-	Grant Received	20,00,000.00
31,89,950.00	Donations Received	17,32,210.00
5,69,482.02	Other Income	5,92,141.89
37,59,432.02	Total	43,24,351.89

EXPENDITURE

2008-2009 Amount In INR	Particulars	2009-2010 Amount In INR
-	NRTT Prgramme Expenses	5,39,988.00
3,01,270.00	Other Programme Expenses	3,40,712.00
8,40,395.00	Personnel Cost Other than Grant	12,76,900.00
4,49,499.80	Admin Expenses Other than Grant	13,59,740.95
14,502.00	Depreciation	80,138.00
21,53,765.22	Excess of Income over Expenditure	7,26,872.94
37,59,432.02	Total	43,24,351.89

LIABILITIES

2008-2009 Amount In INR	Particulars	2009-2010 Amount In INR
23,70,360.00	Trust Fund	23,70,360.00
20,65,001.31	Revenue Accumulation	13,75,652.25
-	NRTT Project Grant Balance	14,16,222.00
73,045.00	Current Liabilities	3,45,492.00
45,08,406.31	Total	55,07,726.25

ASSETS

2008-2009 Amount In INR	Particulars	2009-2010 Amount In INR
46,552.00	Fixed Assets	6,40,890.00
35,52,433.50	Investments	22,55,955.06
3,04,402.00	Current Assets other than Cash and Bank Balance	2,49,476.93
6,05,018.81	Cash and Bank Balance	23,61,404.26
45,08,406.31	Total	55,07,726.25