2018-2019

CHEYUTHA FOUNDATION For Organ Transplants

A Passion to Help Annual Report – 2018-2019

Cheyutha Foundation for Organ Transplants (CFOT) is a social organization formed by Renal Transplant Recipients and is spread across Telangana and Andhra Pradesh states. The main motive of our society is to support patients suffering from kidney diseases requiring dialysis or transplantation.



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Cheyutha Foundation for Organ Transplants

Annual Report - 2018-19

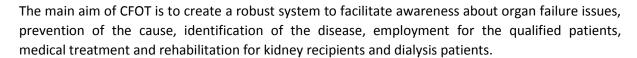
From the Founder's Desk

Cheyutha Foundation for Organ Transplants (CFOT) is for people like me, whose lives have been changed irrevocably owing to kidney disease.

I was diagnosed with polycystic kidney disease during my student days. The discovery traumatised my entire family. It costed some relationships that were close to my heart. I battled with the disease for some time and managed to undergo a transplant when my aunt donated her kidney. She is my saviour. She gave my life back.

It was a tumultuous journey. This journey made me go through the trauma of dialysis patients and kidney recipients. I experienced the difficulty in managing finances for medical care, pre- and post-transplant challenges, unemployment, long cycles of treatment, the subdued life and a lot more. In fact, a near unsurmountable wall of challenges. It led me to think, to rise and to extend a hand to support organ receivers. That's how **Cheyutha Foundation for Organ Transplants** was born.

"I experienced the difficulty in managing finances for medical care, pre- and post-transplant challenges, unemployment, long cycles of treatment, the subdued life and a lot more. In fact, the near unsurmountable wall of challenges. It led me to think, to rise and to extend a hand to support organ failure and organ receivers. That's how Cheyutha Foundation for Organ Transplants was born". --Bhagawan Reddy



CFOT was started in 2015 and formally incorporated as a society in January 2018.

We are a community consisting of patients suffering from CKD, family members of CKD patients, doctors, stakeholders offering services like treatments, patients-to-hospital connections and relevant medical agencies.

Educating members about the new treatments, supporting the needy patients, providing medicines at a subsidised cost, supplying dialyzer kits to the patients undergoing dialysis and assisting with regular health check-ups are our organisation's top priority.

We are also associated with the "Kidney Warriors Foundation" to extend our services to patients across India.

Message from the Co-founder

Cheyutha Foundation for Organ Transplants (CFOT) is an organisation which opened doors to all the kidney patients who could not afford dialysis, kidney transplant, treatments, and medical support. I was diagnosed with IGA Nephropathy and was the Jeevandan Organization helped me secure a kidney.

My disease and the path to recovery inspired me to join Bhagawan Reddy in supporting kidney patients and organ donation.

"IGA Nephropathy ruined my entire career and lost my hope. I received a cadaver organ. Since my parents were unfit to donate a kidney, I choose Jeevandan as an alternate route to receive a kidney.

I registered in both Telangana and Andhra Pradesh states for a cadaver organ. By God's grace, a young boy (braindead) gave me a life back by donating his organs in Andhra Pradesh. The transplant gave me a boost to start the "Cheyutha Foundation" with Bhagawan after we met unexpectedly.





What We Do

Vision

Our vision is to save and improve the lives of patients with chronic kidney diseases (CKD).

Mission

Our mission is to educate, support, research and improve kidney health.

How We Came into Being

A proposal started in 2015 with a small meet up with a transplant recipient Mr. Bhagavan Reddy (Founder) and a dialysis member Mr. Kiran (Co-founder) at NIMS hospital to save and improve the lives of kidney patients.

We started with a WhatsApp group of ten members. Within a short period, we have gathered more than 350 transplant recipients, more than 160 dialysis members, a couple of nephrologists and dialysis technicians.

Our vision was formalised when we formed the Cheyutha Foundation for Organ Transplants in 2018.

Focus

Our focus is to:

- 1. Create awareness about the End Stage Renal Disease (ESRD) by conducting workshops and events.
- 2. Conduct camps to educate people on organ donation in Telangana, Andhra Pradesh and all over India.
- 3. Empower patients through education about the resources available for kidney patients in the form of government subsidies, Employees' State Insurance (ESI) benefits, availability of medicines, resources, and infrastructure in hospitals and clinics.
- 4. Conduct workshops and events to know the impact of the disease and how to prevent the disease.

- 5. Gather information and updates on the science of kidney failure, constant update of knowledge and on-going research on kidney failure and disseminate information among patients in India and if needed beyond the boundaries of India.
- 6. Interact with patients to bring change in diet, medications, tests essential for combating the disease and understand the issues faced by patients.
- 7. Provide financial assistance to kidney patients and their relatives.
- 8. Conduct discussions, meetings, workshops, seminars, events, and conferences to increase the reach of the society's work.
- 9. Help patients get jobs so that they can be financially independent.
- 10. Distribute medicines, dialysis kits at subsidised rates, rehabilitate kidney transplant recipients and dialysis patients and arranging follow-up health check-ups for them.
- 11. Promote and create awareness of organ transplant/donation, blood donation camps, health check-up camps.
- 12. Make efforts to ensure that the Government of India, the public sector industries, and private sector industries recognise CKD patients by providing them with special arrangements to manage their healthcare and rehabilitate the patients.
- 13. Interact with Government bodies on matters of organ transplant, change in organ donation laws, bringing relief through labour laws, trade duties, and exemptions that the society deems to be necessary for patient rights and dignity.
- 14. Motivate government, private, and public sector employers to give opportunities to transplant and dialysis patients to work.

Activities

1. Launched our logo at Taj Deccan, Hyderabad, on 23rd February 2018, by Kidney Warriors Foundation Media Coordinator, Anjali Uthup Kurian along with our Board members.





2. We conducted several meetings with kidney transplant recipients to discuss their issues in various locations and hospitals in Hyderabad.



3. We launched our brochure at the BHEL Grounds, Hyderabad in the presence of CFOT members. Also, we distributed medicines to needy patients. Twenty-five members participated in this event.



4. We organised a meeting in Shamshabad on 7th January 2018 with 24 Kidney Transplant recipients, 2 organ donors, and 2 family members of the recipients and took the initiative to register as an NGO.





5. We conducted board meeting in Mumbai on 14 January 2018 with Kidney Warriors Foundation, All India Organisation Working for Chronic Kidney Patients and Cheyutha Foundation for Organ Transplants founder who is also a Telangana State Co-ordinator for Kidney Warriors Foundation. CEO, Founder and Author Ms. Vasundhara Raghavan and a kidney donor for his son attended the board meeting. In the meeting, we discussed kidney patients' issues and raising memorandums to the health ministries to solve the problems.





Events

1. We organised an event in ESI with patients and reputed doctors. Educated kidney transplant recipients and dialysis patients about kidney health. *Dr. Sree Bhushan Raju, Nephrologist, NIMS Hospitals,* and *Dr. T. K. Saha, Nephrologists, Apollo Hospital, Dr. Rajashekara Chakravarthy, Nephrologist, Star Hospital, Dr. Vikranth Reddy, Nephrologist, Care Hospitals, Mrs. Siva Parvathi, Kidney Transplant coordinator, NIMS Hospital, and Dr. Ms. Alekya, dietician talked about kidney diseases, awareness, organ donation, transplants, dialysis and educated the patients who attended the event.* We also organised the registration of patients, Kidney Warriors book launch and launched Cheyutha website. The **kidney transplant recipients** shared their experiences in the event. CFOT Founder, Mr. Bhagavan Reddy and team organised awards and felicitation ceremony to all the Doctors panel and participants.





Nearly 173 Kidney Transplant Recipients, 32 dialysis patients, and few dialysis technicians, patient family members participated in this event.

2. We distributed free medicines to the patients at the monthly meet at BHEL, Hyderabad.





3. We organised Kidney Talk at the Star Hospitals, Hyderabad. More than 100 kidney patients attended this event. We distributed jute bags to patients and caregivers.



4. NGOBOX organised the Deccan CSR Summit meeting at Hyderabad. We participated in this event to improve our services and understand the services offered by other NGOs as well. "Acquired the knowledge through CSR Deccan summit."



5. We held an awareness meeting for kidney patients at the ESI Hospital, Sanath Nagar, Hyderabad.



6. We distributed medicines at Siddipet for kidney transplant patients.



కిడ్డీ రోగులకు మందుల పంపిణీ



కిడ్నీ మార్పిడి రోగులతో ఫౌండేషన్ సభ్యులు

సిద్దిపేట రూరల్ : సిద్దిపేట ప్రాంతంలో ఉన్న 25 మంది కిడ్నీ మార్పిడి రోగులకు చేయూత ఫౌండేషన్ ఆధ్వర్యంలో మందులు పంపిణీ చేశారు. ఈ సందర్భంగా ఫౌండేషన్ అధ్యక్షుడు భగవాన్రెడ్డి మాట్లాడుతూ.. కిడ్నీ మార్పిడి చేసు కున్నవారికి జీవిత కాలం మందులు వాడాల్సి ఉంటుందని, దీనికి సంబంధించిన కొన్ని మందులు ఫౌండేషన్ తరఫున అందజేస్తున్నామ న్నారు. ప్రభుత్వం నుంచి రోగులకు సహకారం అందించేలా చేయూత ఫౌండేషన్ కృషి చేస్తున్న దని తెలిపారు. ఆర్థికంగా వెనుకబడిన రోగులకు మందుల కొనుగోలుకు ఇబ్బందిగా మారిందని ప్రభుత్వం కిడ్నీ వ్యాధి గ్రస్తులపై దృష్టి సారించి ఆదుకోవాలని కోరారు. కార్యక్రమంలో సభ్యులు కిరజ్, గిరిబాబు, ఇందుటియ పాల్గొన్నారు.

- 7. We conducted monthly meetings with the staff of CFOT, and kidney patients.
- 8. Also, we organised events at:
 - a. Shamshabad
 - b. Siddipet
 - c. Panjagutta
 - d. Dilsuknagar
 - e. Secunderabad
 - f. Sanath Nagar
 - g. Patancheru and

Picture Gallery *ESI Event*

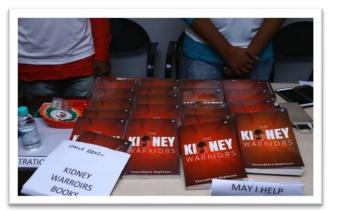




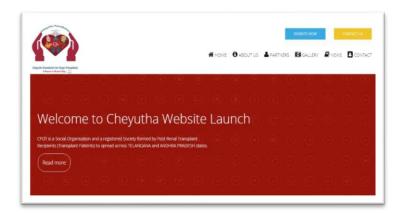




























Awareness Meet













Kidney Warriors Meet







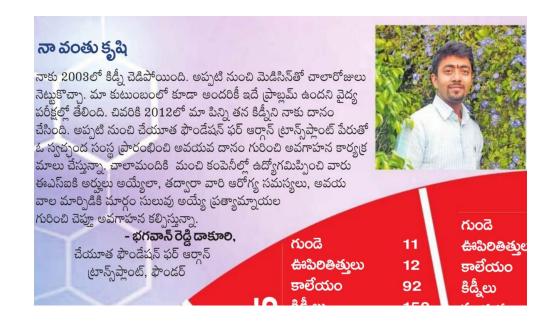




Deccan CSR Summit







What We Do

We are making a difference in the lives of patients who are suffering from kidney diseases and are awaiting a transplant or have received a transplant.

We know that this is a huge challenge. We know that our work yields better results when we join hands with other NGOs who complement our efforts.

Here is a look into what chronic kidney diseases are all about.

About Kidney Diseases and Treatments

Kidney diseases such as Chronic Kidney Disease (CKD), nephrotic syndrome, acute kidney disease and polycystic kidney disease damage your kidneys and affect the waste elimination process in your body.

Consequently, the patient may develop complications like high blood pressure, weak bones, poor nutritional health, and damage to the nervous system. Also, kidney disease increases your risk of cardiovascular diseases.

- A patient can receive a kidney from a living or dead (cadaver) person. It is well known that kidneys from living person function far better than cadaver organs. Consequently, the former has far lesser complications than the latter category.
- According to The Better India (www.thebetterindia.com), more than 1,50,000 Indians are estimated to be in need of a kidney transplant, but only 5000 people receive a kidney.



(Source: https://notto.gov.in/.)

Dialysis

• According to Vikaspedia, an initiative by the government of India, every year about 2.2 Lakh new patients of End Stage Renal Disease (ESRD) get added in India resulting in additional demand for 3.4 crore dialysis every year. With approximately 4950 dialysis centres, largely in the private sector in India, the demand is less than half with existing infrastructure. Since every Dialysis has an additional expenditure tag of about INR 2,000, it results in an annual expenditure to the tune of Rs.3-4 lakhs for a patient. Besides, most families have to undertake frequent trips, and often over long distances to access dialysis services incurring massive travel costs and loss of wages for the patient and family members accompanying the patient. Practically this leads to a financial catastrophe for all families with such patients. With the substantial gain in quality of life and extension of progression-free survival for patients, families continue to stretch financially to make large, out-of-pocket spends.

It has been felt that both in terms of provision of this essential life-saving procedure and also
for reducing impoverishment on account of out-of-pocket expenditure for patients, a dialysis
program is required.

Cost of Dialysis

Treatment	Private Hospital/Month INR	Government Hospital/ Month INR
Dialysis	20,000 to 35,000	8,000 to 10,000
Fistula Surgery cost	15,000 to 30,000	10,000 to 15,000
for safe dialysis		
Medicines	8000	8000

Dialysis restricts patients from having an active life. And the best alternative for dialysis is kidney transplantation.

About Kidney Transplantation

A kidney transplant can free you from long-term dependency on dialysis and the strict schedule that goes with it. However, kidney transplants aren't suitable for everyone. This includes people with infections and those who are severely overweight.

A kidney patient can receive organs from a dead person (cadaver organ) or from a live person (live organ).

Cost of Transplantation

Treatment	Private Hospital INR	Government Hospital INR
Kidney transplantation cost	3 to 6 lakhs	1 to 2 lakhs
Lifelong medication	10,000-15,000 per month (After 5 years this cost will reduce up to 5000-9000 per month)	
Lifelong lab tests and follow-up visits to the doctor	2000 to 3000 per month	

Success Stories

Shashidhar Reddy, Hyderabad

I am Shashidhar Reddy. I am a native of Hyderabad. I studied hotel management. I married Aparna, and my daughter Aparna is in the 5th class. I have 8 years of experience in hotel management.

When I was working in the **Jasmine Restaurant** at Malakpet, Hyderabad, I was diagnosed with kidney failure, and I underwent kidney transplantation in 2012. My mother donated her kidney. I am taking lifetime immunosuppressive medicine from ESI. Since my wife is an ESI beneficiary, as a spouse I am covered for medical expenses.

Once I was travelling with my family from Hyderabad to Suryapet, and I forgot to bring medicine. I was worried. Being a member of **Cheyutha Foundation's WhatsApp Group**, I sent a message to CFOT around 7 o' clock. Immediately, the founder of CFOT replied. He shared the nearby members' contact numbers and asked me to contact them. Luckily one person was using the same medicine I was taking. Though he was away from home, he shared his home's location and asked me to collect the medicine from his home. I felt incredibly happy.

Krishna, Mamidipally, Hyderabad

Mr. Krishna is a newly diagnosed kidney patient from Mamidipally Village, Shamshabad Mandal, Rangareddy District. His parents are illiterates, and they are daily wage labourers in Airport Landscaping. They approached Cheyutha Foundation's executive members for help. Our members counselled them on organ donation and Krishna's health. Though his mother and father agreed to donate a kidney, unfortunately, his blood group did not match.

Then, CFOT completed his registration process under the JEEVANDAAN Scheme (A Government of Telangana Initiative). Now he is in the queue to receive a kidney for transplantation.





Mohammad Iftekhar uddin, Langer House, Hyderabad

I am Mohammad Iftekharuddin from Langer House, Hyderabad. I completed my graduation. I got married and have a daughter. Before I manifested the disease, I worked as an electrical draftsman in Sharjah, UAE. My salary was 3500 AED per month (approximately INR. 65,000). My disease was diagnosed in the year 2001, and I lost my job in UAE, and I had a host of problems like dialysis, fistula surgery and cadaver organ registration process and transplantation procedure.

I was **on dialysis for six years,** and I spent around Rs. 50000 per month for dialysis, and transplantation with the help of CMRF (CM Relief Fund). I got cadaver transplant on 30th January 2017 at Care Hospitals, Banjara Hills, Hyderabad.

From dialysis to post-transplantation there was no source of income for my family and I spent more than I earned for my treatment. My family had to face some horrible situations, and I started searching for alternative income sources. Fortunately, I met the founder of CFOT, and he added me in CFOT's WhatsApp group. Usually, CFOT executive members always keep posting new job opportunities for unemployed transplant patients. One such post helped me to apply for a job in Reliance Digital.

When I attended the interview, the recruiters refused to employ me though I qualified for that job. Then I passed this information to the founder of CFOT Mr. Bhagawan Reddy. He helped me to get that job. Currently, I am working with Reliance Digital, Attapur, Hyderabad and getting a salary of INR 17,000 per month and now I am an ESII beneficiary. I am taking lifetime immunosuppressive medicine from ESII. Now my family is living happily.

I am very thankful to CFOT for helping me go back to work.

Information about the Players in Organ Transplantation

We have been educating patients and their families about the following facilities available for patients.

How to Donate or Receive an Organ

Most of the patients don't know about the government schemes that facilitate organ collection from **Brain dead people and other donors. Today,** all the state governments and government of India are running various schemes for organ collection and send the same to hospitals for patient transplantation:

National Organ and Tissue Transplant Organization (NOTTO) is a national level organization set up to support coordination and networking for procurement, allocation and distribution of organs and tissues. It maintains a national organ & tissue transplantation registry and a national biomaterial bank, also known as the national tissue bank.

<u>Jeevandan</u> proposed by the Cadaver Transplantation Advisory Committee (CTAC) gives a fillip to organ transplantation. Jeevandan is a state-level organisation set up in Andhra Pradesh and Telangana.

Motivating Families for Live Organ Donation

Motivating family members to donate their organs and save diseased patients in their family.

Government Schemes

Chief Minister's Relief Fund (CMRF) and health schemes offered by governments of Telangana and Andhra Pradesh provide various degrees of coverage. Some schemes are:

- Employee Health Schemes
- Arogya Sri Scheme for the poor below the poverty line
- Employees' State Insurance (ESI)scheme

Public Transport

Indian railways provide free or concessional travel facilities to patients and caretakers.

The Ministry of Railways offers concession in basic mail/express fares to kidney patients when travelling alone or with an escort, for dialysis, kidney transplant operation.

The element of concession will be 75 % in first class, AC 3-tier, AC chair car, second class sleeper and 50% in AC first class & AC-2 tier sleeper. The same concession will be possible for return also after dialysis and kidney transplant operation. One escort with every patient will also be eligible for the same concessional fares.

Subsidised Medicine

Govt. of Telangana is providing immunosuppressive medicine to BPL category people through the Arogya Sri Scheme. In this regard, we are guiding patients to collect medicine from Arogya Sri.

We are also providing Subsidised Medicine with the support of our executive members.

Blood Donation Awareness Camps

We organise blood donation camps and arrange for blood in case of an emergency for kidney patients. We have a tie-up with Ram Blood Bank in Hyderabad to support us.

Organ Donation Awareness Camps

We conduct awareness camps in corporate offices and colleges with the "Be an Organ donor" caption.

Health Awareness Camps

We organise health camps in rural areas to educate people in far-flung areas.

Conducting Job Fairs

We mobilise unemployed patients and invite employers to recruit suitable candidates through appropriate events.

We post new recruitment news in our social media groups and send candidate resumes to HR Departments.

Creating Placement Opportunities

We motivate employers to provide opportunities to patients and patients to work and sustain their life through the employee benefits such as ESI enrolment to get free medicines and lab tests.

Partner Search

We contacted the organisations listed below and explored opportunities for partnerships.





















Partners Engaged

- Kidney Warriors Foundation, All india
- Kidney Patients Support Foundation, chennai
- Human Care foundation, delhi
- Kidney foundation, Kerala
- Sunny foundation, Kerala
- Kidney Care Foundation Society, Rajasthan
- LIFE NGO, Telangana

How to Donate and Volunteer with Us

To help our cause, you can either volunteer or donate.

To volunteer, call:

Mr. Kiran Kumar, +91-9491819491

Mr. Bhagavan Reddy, +91-8328605200

To donate, use the following details:

BANK NAME: VIJAYA BANK

ACCOUNT NUMBER: 409401011002273

IFSC CODE: VIJB0004094

PAYEE'S NAME: CHEYUTHA FOUNDATION FOR ORGAN TRANSPLANTS

BRANCH: SHAMSHABAD



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