



# Annual Report

## 2018-2019

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# ABOUT CONGENITAL HEART DISEASE

Congenital Heart Defect, also known as a Congenital Heart Anomaly or Congenital Heart Disease (CHD) is a problem in the structure of the heart that is present at birth. CHDs are the most common types of birth defects. These defects can be in the walls of the heart (resulting in hole in the heart), the valves of the heart (resulting in blockage or leakage), the arteries and veins near the heart, which disrupts the normal flow of blood through the heart. The blood flow can slow down, go in wrong direction or to the wrong place.

## FACT SHEET

- **1 in 100 children are born with Congenital Heart Disease**
- **Approximately 1,80,000 to 2,00,000 children are born with CHDs each year in India**
- **Only 10,000 to 15000 children are able to access treatment**
- **Rest either do not survive or get added to pool of children waiting for their treatment**

Congenital Heart Defects affect a large number of new born in India and accounts for a high proportion of infant mortality nationally. There are regional differences in the prevalence and distribution pattern of Congenital Heart Defects. The majority of CHD cases are diagnosed between the age group of 0 to 5 years. The lack of experts and specialist in Pediatric Cardiology severely affects the accessibility and early detection of cases of Congenital Heart Disease.



## SIGNS AND SYMPTOMS OF CHDs

The signs and symptoms of Congenital Heart Disease are as follows

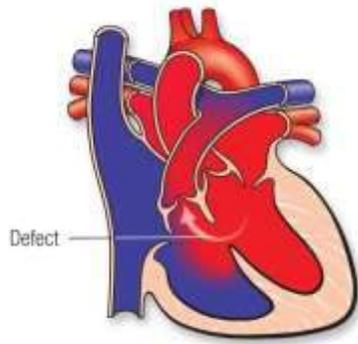
- A bluish tint to the skin, fingernails and skin(The medical term used by doctors is Cyanosis - a condition caused by lack of oxygenated blood)
- Fast breathing and poor feeding
- Poor weight gain
- Recurrent Lung infections
- Inadequate blood circulation



## SCREENING AND DIAGNOSIS

The different test for diagnosis of CHDS are as follows

- **Echocardiogram:** A type of ultrasound that takes pictures of your heart. There are different kinds, so ask your doctor what you can expect.
- **Cardiac catheterization:** A doctor guides a very thin, flexible tube (called a catheter) through a blood vessel in the child's arm or leg to reach the heart. Dye is put through the catheter and then X-ray videos are used to see inside of heart.
- **Chest X-ray:** These can reveal signs of heart failure .



## KEY CHALLENGES IN TREATMENT OF CHDs

- **Lack of awareness and delay in diagnosis:** A substantial proportion of births in India occur at home, and the infant is likely to die before the critical, ductus-dependent CHD is diagnosed. Fortunately, the rate of hospital deliveries have significantly increased due to several incentivized schemes by the Government of India. However the general masses are ignorant about the prognosis of the disease and number of them believe that a child with CHD is doomed and will never be able to lead a fruitful life, even if intervened. Delay in referral results in poor outcomes as complications and co-morbidities (such as under- nutrition) may have already set in.
- **Lack of Infrastructure and resources:** The resources for treatment of CHD are not only inadequate but also seriously mal-distributed. The geographical distribution of the treatment centers is very uneven. Poverty, which is the greatest barrier to successful treatment of CHD is more common in states with little or no cardiac care facilities. Transport of newborns and infants with CHD is another neglected issue in India. There is practically no organized system for safe transport of newborns and infants with CHD.
- **Financial Constraints:** In most instances, families are expected to pay for the treatment out of their pocket, which they can barely afford. Approximately half of the families borrow money during the follow-up period after surgery .Many families lose their wages as they are away from work during care of these children. The number of public hospitals which provide care at a low cost are very few. Most cardiac centers, especially those set-up more recently, are in the private sector and may not be affordable for the majority. Public hospitals are faced with a very large number of patients and have waiting lists ranging from months to years



# ABOUT CHILD HEART FOUNDATION

## Our Vision

-  Early diagnosis of child heart disease (CHD) in India, appropriate treatment of CHD with internationally accepted mortality and morbidity
-  Pediatric cardiac treatment should be within reach of every child irrespective of their financial status and economic background
-  To have regional Pediatric Cardiac Centers in all states where economically challenged patients can seek best of treatments without spending a single penny

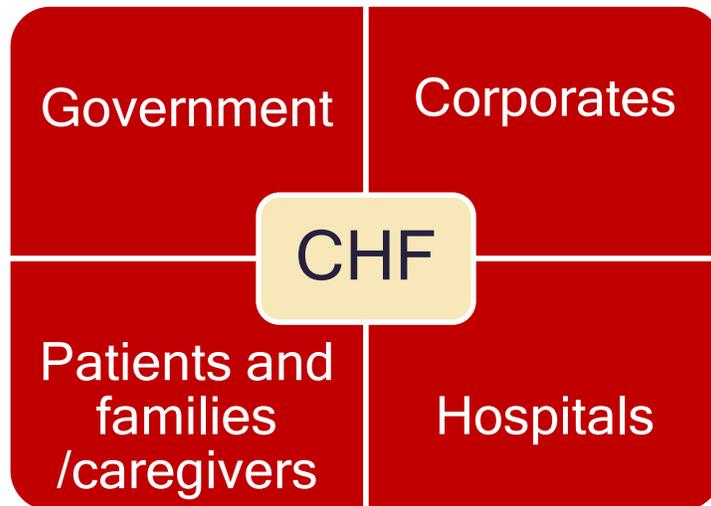
## Our mission

-  To treat each and every child with heart disease
-  To educate the next generation of leaders in child health care, define and cascade steps for creating pediatric cardiac center's in all the cities of India with the aim of working specifically for underprivileged people
-  Sharing the knowledge of Pediatric Cardiology amongst medical community to improve awareness and early diagnosis
-  To uplift Pediatric Cardiology through technological and scientific advancement to achieve international standards of care
-  Becoming a helping hand for the government bodies for treatment of marginalized children born with CHD

## OUR VALUES



## OUR STAKEHOLDERS



# OUR GOVERNANCE

## (A) ABOUT OUR TRUSTEES

### **Professor Subash Kashyap (President, Child Heart Foundation)**



He is a retired physics professor from IIT Delhi. He has a strong educational background and a vast teaching experience in the field of physics. He served as director at Kamla Nehru Institute OF Technology n Sultanpur in 1998-1999, dean in faculty of Engineering, RML, Avadh University, Faizabad (U.P) in 1998-99 and professor in IIT Delhi in June 2011.

### **Dr. Vikas Kohli(Founder Trustee, Child Heart Foundation)**



One of the most renowned Pediatric Cardiologist in Delhi. His major expertise is Interventional Pediatric Cardiology and his interest lies in Neonatal Cardiology, Fetal Cardiology and to improve Neonatal Cardiac survivals in developing countries. His area of interest is in Interventional Pediatric Cardiology; his current area of interest is in Neonatal Cardiology; Fetal Cardiology (Fetal Echocardiography) and improving neonatal cardiac survivals in developing countries.

### **Varsha Bengani(Treasurer)**



She is commerce graduate from Delhi University and has a diploma in Fashion Designing. She is a dedicated homemaker with a loving and supportive family. She has been actively involved in the social work since the last 10 years

### **Pallavi Bharadwaj**



She is a health and lifestyle coach in India. After completing her studies in nutrition in U.S.A and UK, she is practicing as successful holistic health and a lifestyle coach.



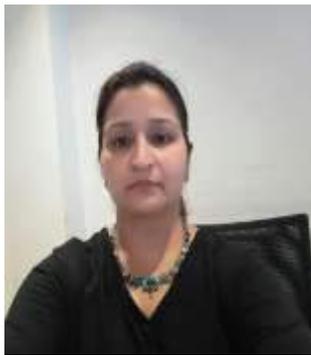
**Dr. Poonam Kohli**

She is an American Board certified Child specialist practicing in Delhi from last 15 years. She has trained in Jackson Memorial Hospital, University of Miami, USA for 3 years. She has worked in Pediatric Cardiac Intensive care at Kolkata for 2 years, Doha Qatar New born ICY for 2 years & Riyadh Saudi Arabia for 2 years. From last 15 years, she is serving patients in India.



**Sonal Nagpal**

She plays a dual role of a homemaker and a professional. She has worked for twenty years as a Project manager in the delivery lead in the field of content development and E - learning and has worked with brands such as IBM and NIIT. Her forte has always been dedication towards work and commitment towards delivery excellence and client satisfaction. She is passionate towards child and maternal health issues.



**Neetu Tyagi**

She has strong background of social work and has been active in welfare services of children. She has done M.S.C in human development and has been working for the last 8 years in the field of research and development. Her research papers have been published in several journals and publications

## **(B) BOARD OF ADVISORS**

### **(I) Mr A.K Nair**

Mr Nair is the Director of A. K. NAIR & Co, a firm of Chartered Accountants established by persons having a collective professional experience of over 40 years in providing specialized services in the field of Management Audits, Taxation, Company Law Matters, Corporate Services, Project Development and Financial Consultancy.

## (C)OUR TEAM

### **Ms. Sunita Harkar Shalla, Head of Operations**



“Looking at the relieved and happy faces of parents who bring their child for regular follow up after successful treatment reassures me that joining Child Heart Foundation has been one of my best decisions in professional life so far”.

A post graduate in pharmacy with a Diploma in Human Resource Management she has more than twenty years of experience in research, academic and social work. She joined Child Heart Foundation in Feb 2018, She was working in Cancer Awareness and Prevention organization before joining CHF

### **Pragyan Parimita, Assistant Manager - Administration**



She has done her Post Graduate in Business Administration and have acquired 7 years of experience in the field of Human Resource. She started her journey with not for profit organization as Research Associate and has joined the team of Child Heart Foundation as Assistant Manager, Admin in May 2018. She is confident and dynamic. She believes that work is body's best prayer to the divine and when you work for a genuine cause, it adds wings to your life.

### **Ashok Varshney, Senior Executive - Digital Communications**



He has 6 years of experience in Digital Marketing and Communications. He has the experience of designing content for reputed organizations such as Markup Design Private Limited, Home Shop 18, Dainik Jagran Prakashan and Wildnet Technologies Private Limited

### **Abhijit Sarkar, Senior Project Manager, Child Heart Foundation**



He has 7 years of experience in the development sector. He is working in Child Heart Foundation as a senior manager and is involved in project conceptualization, function of the day to day operations, volunteer management and event coordination etc.

## LIVES WE HAVE TOUCHED



### **Ampriyal**

Ampriyal was diagnosed with congenital heart disease when he was 4 months old, which if not treated timely could have led to heart failure. His parents working as tea pickers earned up to Rs. 150 a day. With such minimal wages they were not able to afford the surgery for Ampriyal which was estimated around Rs. 1,60,000. Just as the family was running out of hope, they got in touch with the Child Heart Foundation for financial help. CHF actively worked in helping the family generate funds for their child's surgery. Ampriyal is now healthy and doing well.



### **Sophia Burman**

Sophia underwent two heart surgeries at the age of two and the half years. She needed an emergency third surgery to repair the defect which her parents were unable to afford with an estimated cost of Rs 2.75 Lakh. Child Heart Foundation supported Sophia in undergoing her treatment and also coordinated the surgery. Today Sophia has full recovered, goes to school regularly and has dreams of becoming a doctor



### **Anand Lepcha**

Around 6 months after birth, Anand was diagnosed with a Patent Ductus Arteriosus which adversely affected functioning of his heart and lungs. His father works as a watchman in a private firm and was unable to bear the cost of his treatment. Child Heart Foundation registered the child under CHF HriDAAN and helped in raising funds for the surgery of the child



### **Raghav**

Raghav was detected with PDA, a form of CHD, when he was 3 months old. Raghav had recurring fever, breathlessness and severe pain. The estimated amount for the surgery was Rs. 1.8 Lakhs. His father lost his job and his mother worked as a cook. Getting the amount seemed an impossible task. When all hopes were lost, CHF came forward to provide a helping hand to family and they were able to avail the financial support that they required to save their child.

### Pihu Jaiswal



She was .7 years old when was detected with Tetralogy of Fallot(TOF) - A rare condition caused by a combination of four heart defects that are present at birth. She got exhausted easily and her skin, nails and lips turned blue. The doctor told the parents that an urgent, open heart surgery is required to save Pihu's life. The estimated amount for the surgery was Rs. 3.2 lakhs. Child heart Foundation reached out to the family with the support that they desperately required and was able to help them in getting the treatment of their child done successfully.

### Kartik



Kartik, 7-months-old, was detected of Ventricular Septal Defect. He was suffering from pain and breathlessness. He required urgent surgery to be able to live and the amount of money required for the surgery was Rs. 3 lakhs. In their moment of despair, Child Heart Foundation came forward to provide the support that the family required to help them save their child. CHF helped them generate the funds that was needed for the surgery. Now, Kartik is well and healthy.

### Yuvaan Paswan



Yuvaan was detected with VSD - a heart defect due to abnormal connections between the chambers of heart at the age of 2 years. He was always exhausted and fatigued. The doctors recommended medicines in the initial stage, but was told for an urgent surgery. The amount estimated for his surgery was Rs. 3 lakhs. Child Heart Foundation reached out to the family in time to help them with the financial backing they required in order to give their child a happy and pain free life.

Other children supported under the CHF HRIDAAN Program are as follows

S.no	Name	Hospital
1	Samim Latif	Narayana Hospital
2	Angshu Debnath	Dr. Chhang's Super Speciality Hospital
3	Gunjan Darji	Dr. Chhang's Super Speciality Hospital
4	Shalu Kumari	Sri Satya Sai Hospital
5	Yuvaan Paswan	Narayana Hospital, Bangalore
6	Raghav	All Indian Institute of Medical Sciences
7	Kartik	All Indian Institute of Medical Sciences
8	Avirup Adhikari	Dr. Chhang's Super Speciality Hospital
9	Abhir Kumar	Apollo Hospital
10	Viraaz Bansal	Apollo Hospital
11	Satwinder	Apollo Hospital
12	Ayman	Escorts, Faridabad
13	Khushi Singh	Apollo Hospital
14	Chasmenur Begum	Dr. Chhang's Super Speciality Hospital

## HOW WE WORK

**Step 1 :** Free / discounted OPD on every thursday in Delhi and twice a month at Punjab and Siliguri under PraDAAN Program

**Step 2 :** The patient diagnosed with Heart Defects as a result of free / discounted OPD are registered under the CHF HRIDAAN Program

**Step 3 :** Filling and scrutinizing the required documents which includes income certificate of the parents, address proof, copy of aadhaar card and date of birth certifiante

**Step 4 :** Taking informed consent from the family to use the pictures and videos for fundraising

**Step 5 :** Initiating fundraising through different models

**Step 6:** Referral to specilaized hospital for facilitating treatment procedures

**Step 7 :** Continous communucation with the family and facilitating free follow up visits

## OUR PROJECTS



**PradaAN:** Under this programme the patients from remote parts of the country and underprivileged background are provided free/ discounted OPD for diagnosis of Congenital Heart Defects (CHD) on every Thursday. A fixed day has been allotted for this OPD service keeping in view the challenges faced by underprivileged communities in reach to the designated centres of Child Heart Foundation located in Delhi, Punjab and West Bengal from remote locations and allows them to plan the visit. The Screening is done through Echocardiography which is a diagnostic tool to diagnose any heart abnormality among infants and children.



**Jeevansh :** Under this programme a free of cost screening service is provided to pregnant women from economically weaker section. The patients are referred through independent gynaecologist, government hospitals and private clinics etc. The beneficiaries undergo fetal echocardiography through which a heart health assessment of the unborn baby is done. The results of the test are effectively communicated to the expecting parents along with a treatment plan through a one to one counselling process.



**CHF HRIDAAN :** Under this programme the patients with Congenital Heart Defects are identified under the Pradaan Programme are registered for further treatment and support. The registration process involves verification of documents and validation of income proof. The parents / caregivers of the patients are also counselled about the fundraising process and the process associated with it such as granting of informed consent by the parents or caregivers, process of obtaining referral letters etc. A rigorous online counselling process has been developed by Child Heart Foundation under which representatives of Child Heart Foundation periodically counsel the caregivers and families and share the regular updates in which the status of the fundraising process is shared.

## OUR PROJECTS



**SUGYAAN:** Under this programme awareness about causes of heart ailments is generated through seminars, workshops, guest lectures and sessions. The objective of the programme is to disseminate knowledge about the symptoms of health diseases, role of health diet and lifestyle in addressing heart ailments and treatment procedures etc. The target audience of the programme is diverse and includes - students, working professionals, entrepreneurs and retired professionals etc.



**Hridya Saksham :** This is a specialized echocardiography training program for paediatricians and neonatologists for early diagnosis of Congenital Heart Diseases. We have trained approximately 50 doctors through this training program and have approached state governments to partner with us for echocardiography training at primary health centres, urban health centres and mohalla clinic to ensure screening and diagnostic facilities of CHDs at grassroot level



**PH life Care :** Pulmonary Hypertension (PH) is a rare life threatening disease. In this condition the heart needs to work harder to pump blood to the lungs. The patient need daily medications to maintain a normal life. The lack of awareness about the disease among people make it difficult for people to access treatment on time. The need to take daily medications severely effects the accessibility of treatment among families facing financial distress.

## OUR EVENTS



**Airtel Delhi Half Marathon:** We at Child Heart Foundation participated in Airtel Delhi Half Marathon held in Delhi. There were more than 100 supporters running for our cause. We managed to raise more than 5 lacs as donation amount. Mr Arun Begani was our CHF Silver Champion and Ms. Radhika Bharatram was our ambassador for the event. We managed to get a very good media coverage during the event



**Theatre for Change :** We had a successful fundraising event on February 3, 2019 at IIT Delhi Auditorium. This was done through a comedy play named - "Shaadi Ka Siyappa" which was performed by 'AARAMB-' a group of female theatre artists . We managed to raise more than 6 lakhs through ticket sale and donations.



**Awareness Programme on CHD :** A Community Health Awareness Programme was conducted at Hotel Royal Plaza CP on December 3rd, 2018. Approximately 300 people participated in the awareness programme and learnt about symptoms, risk factors and treatment of Congenital Heart Defects



## ADVOCACY AND SOCIAL ACTION

Children with heart disease are most likely to lead a normal life after successful heart treatment. Pediatric Cardiologists and Surgeons work hard to make this happen. Medicines are an essential part of treatment and result in improvement of a child with heart disease.

**Life saving medicine for kids with heart diseases not available in the market, please help**



Of these medicines, Furosemide (Lasix, Furoped, and other brand names) form the cornerstone of treatment. Due to price control, the only syrup form of this medicine which used to cost Rs 107 per bottle was reduced to Rs 9 per bottle by NPPA. For this reason, the manufacturing of this medicine by SAMARTH Pharmaceuticals was stopped.

In view of the above challenges Child Heart Foundation started an online petition and it was addressed to National Pharma Price Control Authority, Prime Minister, Health Minister and other senior Government officials . The key points mentioned in the petition were as follows

- Not to consider pediatric medicines in the same bracket as adults
- If only one formulation is there in the market it is imperative for NPAA to discuss and deliberate with Pharmaceutical companies and non - profit organizations before taking a decision
- Immediately take measures to get Furoped syrup in the market

As a result of the continued advocacy and awareness efforts of Child Heart Foundation a formal reply from NPAA was received by Child Heart Foundation. The Furoped syrup was also redistributed in the market which ensures that the lifesaving drug is available in the market for children with heart disease.

# IMPACT, CHALLENGES AND WAY FORWARD

## Impact

Program	Number of Beneficiaries
PradAAN (Free Pediatric Cardiac OPD)	1361
JEEVANSH(Free fetal echo for pregnant females )	105
CHF HRIDAAN(Financial assistance for treatment)	20
SUGYAAAN(community awareness program on healthy heart)	>5000
Total lives impacted in 2018-19	6486

## Challenges

- Raising funds for critical cases and emergency situation particularly in circumstances which require immediate medical attention and treatment
- Lack of education and poverty makes it difficult to spread awareness at the community level. Continued awareness is imperative to ensure that delay in screening and diagnosis is combatted
- The lack of trained medical practitioners in the remote villages, slums and resettlement colonies, communities etc. is a huge constraint in making treatment accessible to underprivileged communities

## Way Forward

- Increase the number of patients inflow for screening of Congenital Heart Defects and Pulmonary Hypertension
- Raise more funds for emergency cases
- Conduct sustained training programs for pediatricians under HRIDYA SAKSHAM
- Create awareness about Congenital Heart Defects and importance of having a healthy heart

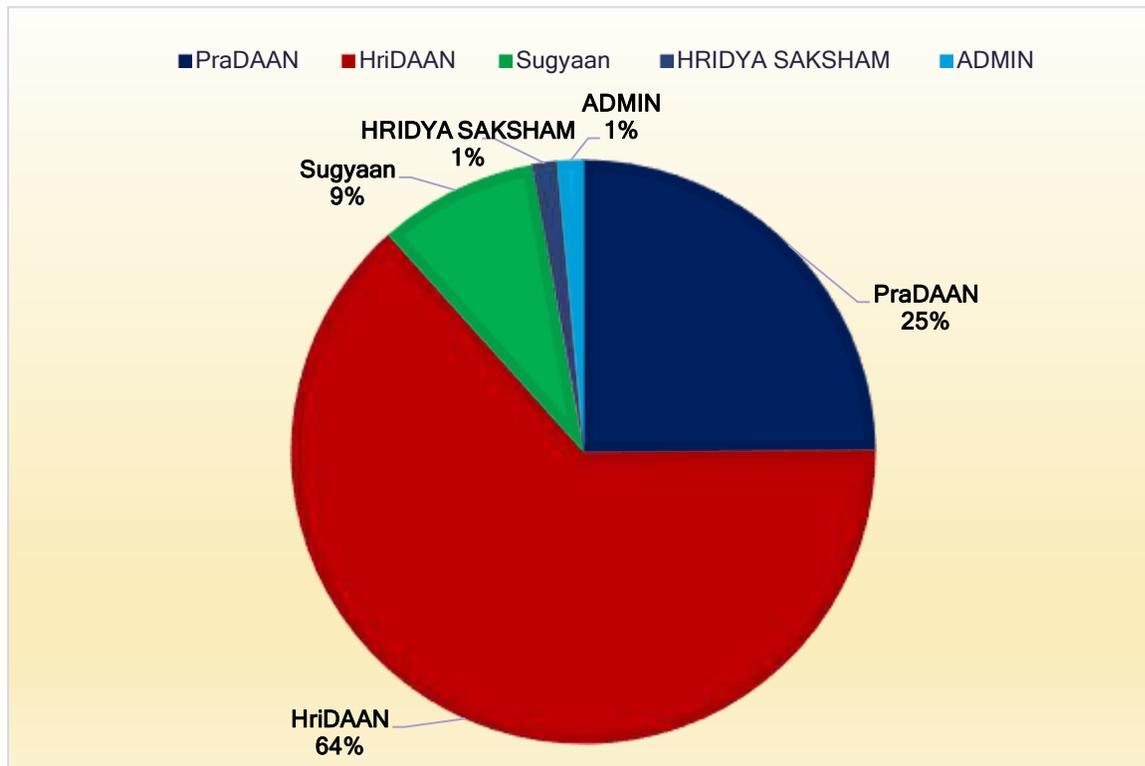


# FINANCIAL SUMMARY

The broader heads under which funds raised were utilized are as follows

- PraDAAN™
- CHF HRIDAAN™
- SUGYAAN
- JEEVANSH
- Hridya Saksham
- PH Life Care

The breakup of the funds utilized has been as follows





## OUR PARTNERS AND SUPPORTERS




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Frick India limited is a public limited company incorporated in the year 1962. Under its Corporate Social Responsibility Frick India Limited is supporting the HriDAAN Program under which financial assistance is provided to children with Congenital Heart Defects from belong to underprivileged backgrounds

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Sitaram Jindal Foundation is a charitable organization which was started with the sole objective to help with moral and social upliftment of the weaker sections of the society. In the year 2018-19 Sitaram Jindal Foundation supported in treatment of children with Congenital Heart Defects from underprivileged backgrounds

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Smile of Hope is a registered international charity to relieve the needs of children with life limiting illness and their families. The charity has partnered with us supported us in treatment of children with Congenital Heart Defects under the CHF HRIDAAN Program

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There are many anonymous individual donors and supporters who have contributed in different ways to give smile to our little hearts

You can donate through following details

#### NEFT

Bank Name: HDFC Bank  
A/c No: 04822560000811  
A/c name: Child Heart Foundation  
IFS Code : HDFC0000482

**paytm**  
Accepted Here

To Pay, Scan  
QR Code in Paytm App



CHILD HEART FOUNDATION

#### Online donations

<https://www.childheartfoundation.com/donate.php>

For information reach us at

[www.childheartffoundation.org](http://www.childheartffoundation.org), [sunita@childheartfoundation.com](mailto:sunita@childheartfoundation.com)

91-9999142268, 011-40519163