



HRIDAY GĀTHĀ

Let's

CHALLENGE HEART DEFECTS

Together



Editor: Jonali Choudhury
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HRIDAY GĀTHĀ



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Let's Understand **CHD**

Congenital heart defects (CHDs) are problems with the structure of the heart. Congenital means present since birth. These defects happen when the heart does not develop normally during pregnancy. It is the most common type of birth defect occurring in about 1% of live births. Congenital heart defects can be Septal defects (means hole in the wall between the left and right sides of the heart), Heart valve defects and Defects in the large blood vessels.

CHDs can range from very mild problems to life threatening problems. Researchers often don't know what causes CHDs. They do know that changes in a baby's genes sometimes cause a heart defect.

Common signs and symptoms of CHDs include cyanosis (meaning a blue colour to the skin, lips and fingernails), fatigue, fast or difficult breathing and heart murmur (unusual sound between heartbeats). CHDs may develop other health conditions too.

Treatment for CHDs depends on the type of the defect and how serious it is. Possible treatments includes cardiac catheterization, surgery, medicines. All children and adults with CHDs need regular follow up with a paediatric cardiologist even if the defect was repaired. Some people may need several heart surgeries or catheterizations over the years. Sometimes they may also need heart transplant.

In India every year more than two Lac children are born with CHDs. One fifth of them have serious defects requiring an intervention in the first year of life. Currently advanced cardiac care is accessible to only a minority of such children.

Increasing awareness of congenital heart defect is likely to be most helpful in early diagnosis and timely referral of cases. We are hopeful that Indian government will provide more training avenues for the budding paediatric cardiologists, paediatric cardiac surgeons, paediatric anaesthetists making paediatric cardiology services accessible to the needy Indian population.



OUR CREATIVE KIDS



Ethan Lakra, 5 years, Kolkata



Ribrib Moonmee, 14 years, Guwahati



Adidev Reddy, 9 years, New Delhi



Adrik Guha, 7 years, Kolkata



Shree Jaganath, 7 years, Puri



Nivan Salvi, 9 years, Thane



Aitijhya Sen, 5 years, Berhampore



Yuvraj, 8 years, Orai (U.P.)



Sirisha Narayana, 7 years, Kanpur



Ayushman Parth, 10 years, Mirzapur



Shreedita Bhattacharjee, 6 years, Udaipur

तू खुद पर रख भरोसा

Qazi Nishat Afza
Kota, Rajasthan

तू खुद पर रख भरोसा,
तेरी मुश्किलें आसान होंगी,
तेरी कोशिशें कामयाब होंगी,
ये मुश्किलें तुझे आजमाएं तो आजमाने दे,
तेरी हिम्मत ही इनका जवाब बनेगी,
और खुद पर शक़ कैसा
तेरी किस्मत तो तू खुद बदल सकता है,
इतनी हिम्मत तो तू खुद रख सकता है,
जिंदगी हर कदम पर एक नया मोड़ लेगी,
कभी हार मिलेगी तो कभी जीत मिलेगी,
तू हौसला रख तुझे कामयाबी मिलेगी,
तू खुद पर भरोसा रख,
तेरी कहानी मिसाल बनेगी.!!



Arrhythmia episode happened on my day.

Appu K George
Ernakulam, Kerala

It was in February 2023. As every year, I was busy with my church days before my birthday, but this year was extra busy as I had scheduled heart meetings in relation to CHD month of February 2023. After coming from work, I went to church for an evening prayer, and when I came home, a surprise cake from my sister-in-law was waiting. Since I had to attend the meeting scheduled at 7:30 pm, I just cut the cake and went online for the meeting, telling them that I would eat it the next day. (Actually, I always had no birthday celebrations except that I go to church and eat my mamma's ordinary yummy cake made for my birthday, but it would be cut as soon as it was made.)

After the meeting and my dinner, I went to bed as I was tired. Actually, for the last few days, I was really tired.

Even though I went to bed, I wasn't able to sleep. By midnight, I felt like my heart was beating faster than normal. But I didn't consider it seriously because I sometimes feel like this, and when I change my sleeping position or have a cup of water, it normally slows down. I did the same—took a glass of water and went back to bed. But I was still not able to sleep. I took deep breaths, etc., but still, I couldn't sleep.

I felt like my heartbeat changed from dup-dup-dup to dupdupdup, and the beats were so strong that I felt my heart was touching my ribs and trying to come out of the rib cage. Yes—it was an arrhythmia episode.

By around 4 o'clock, I went to Mamma and told her I was not feeling well, but as usual, she thought it would be because of my anxiety and told me to try to sleep with my eyes closed. I tried, but by 7 o'clock, I felt no change. I took my pulse oximeter, and it showed O₂ was normal at 95+. So I went on with my routine and decided to take leave from office that day. While having my breakfast, I was not able to eat as there was some discomfort.

Once again, I checked my O₂ level, and it showed normal, but the heart rate was 124, which was abnormal. I just took a pic of it and sent it to my cardiologists. They immediately responded and asked me to take an ECG from my nearby hospital and send the data. I reached the nearby clinic, took the ECG, and sent it to my doctors. Meanwhile, my senior doctor told me to come to the hospital as soon as possible. I called Amma from the clinic and told her to pack a bag for admission in the hospital. We arranged a driver as Pappa couldn't handle the situation, and we went to the hospital. The driver took me there in 45 minutes, and when we reached, all preparations were already done by my doctors for my admission. A resident junior was waiting at the emergency for me, and they took me inside. While shifting to ICU, my senior doctor K. K. Sir was there, even though he was on leave that day. Heart rate was still at 120+. When he saw me, he said, "We can correct it in half an hour, don't worry." In ICU, they started medication, and in two to three hours, the heart rate dipped to 100. A resident doctor, Taniya, was there in ICU monitoring me every fifteen minutes.

During the evening rounds, doctors said they had to monitor me for another 72 hours, and also the IV medicine would take about 48 hours. By night, I felt normal and slept, even with some discomfort like the ongoing medication, change of normal surroundings, beep-beep of monitors, etc.

By the next morning, the heart rate came back to normal, and the doctors said it was an arrhythmia episode. They found the reason for the episode—it was my heart position. Due to my dextro condition, my Fontan was suppressed, which caused my heart to beat more.

I was discharged directly from ICU after the 72 hours, and they made some changes in my sleeping position. But before discharge, on the Echo, they found the normal problems that occur for a Fontan warrior in the long term—that is, mild leakage in the valve and small dilation in the right atrium.

The result of the arrhythmia episode was a change in dosage of medicines, monthly check-ups, etc. But I am doing well now and back to my normal life. Thanks to my doctors for their immediate actions and dedication to me.

My 36th year started with an arrhythmia episode—given by God—reminding me that I am one of His unique creations.

CHD: A Call for Disability Recognition and Support

Qazi Nishat Afza
Kota, Rajasthan

Congenital heart defect (CHD) is a disease present from or before birth that can affect both children and adults. The number of CHD patients is increasing in India, but they are still not recognized as disabled. In India, over 200,000 children are born with CHD annually. About one-fifth of these children have a serious defect that requires intervention in their first year of life.

CHD is a serious disease, and it is a disability that the government should accept as such. It is very disappointing for congenital cardiac patients (children) that the government does not consider it a disability because these children want their rights everywhere, whether it is in a hospital, college, school, or career. This is an internal disease that is not visible. It's in that important organ of the body through which the entire body's functions depend. If your heart doesn't work, then how will you be able to survive? The government should take this seriously because those children have to go through a lot of problems. On the other hand, visible diseases like dumbness, deafness, blindness, etc., are considered disabilities by the government, but CHD is invisible, therefore the government doesn't consider it a disability. This is wrong for those patients who are fighting with congenital heart defects. The government should recognize congenital heart defects as a disability so that CHD patients may get their rights.

For this reason, there are many challenges and shortcomings regarding CHD (Congenital Heart Defect) in India:

1. **Lack of awareness:** There is a lack of awareness about CHD, due to which people are not aware of its symptoms and treatment options.
2. **Lack of medical facilities:** There are not enough medical facilities to treat CHD in India, especially in rural areas.
3. **Lack of specialist doctors:** There is a lack of specialist doctors to treat CHD, due to which patients are not able to get proper treatment.

4. **Expensive treatment:** The treatment of CHD is very expensive, due to which many patients face financial barriers to treatment.
5. **Lack of government support:** There is not enough support and facilities provided by the Government of India for the treatment of CHD.
6. **Lack of testing and diagnosis:** There are not enough testing and diagnosis facilities to diagnose CHD, due to which patients are not able to get proper diagnosis and treatment.

Giving disability recognition to CHD patients can provide them with many benefits, including:

1. **Social Support:** Recognition of disability is necessary to provide social support and facilities to persons suffering from CHD.
2. **Medical Facilities:** Recognition of disability can provide medical facilities and treatment options to persons suffering from CHD.
3. **Economic Support:** Recognition of disability can provide economic support and pension to persons suffering from CHD.
4. **Education and Employment:** Recognition of disability can provide education and employment opportunities to persons suffering from CHD.
5. **Equality in Society:** Recognition of disability can provide equality and respect to persons suffering from CHD in society.

Therefore, it is necessary to recognize CHD as a disability in India to provide the necessary support and facilities to persons suffering from CHD.

Congenital heart defect patients are recognized as disabled in other countries. They are given social support, financial support from the government, and equality and respect in society. Here is the data of some countries where CHD (Congenital Heart Defect) is recognized as a disability:

1. **Canada:** In Canada, CHD is recognized as a disability and the patient is provided with special facilities and support.
2. **United States:** In the United States, CHD is recognized as a disability and the patient is provided with Social Security Disability Benefits (SSDI).
3. **Australia:** In Australia, CHD is recognized as a disability and the patient is provided with Disability Support Pension (DSP).
4. **United Kingdom:** In the United Kingdom, CHD is recognized as a disability and the patient is provided with Disability Living Allowance (DLA).
5. **Germany:** In Germany, CHD is recognized as a disability and the patient is provided with a Disability Pension (*Schrankhelf*).
6. **France:** In France, CHD is recognized as a disability and the patient is provided with a Disability Allowance (AH).
7. **Italy:** In Italy, CHD is recognized as a disability and the patient is provided with a Disability Pension (*Pensione di Invalidità*).
8. **Sweden:** In Sweden, CHD is recognized as a disability and the patient is provided with a Disability Pension (*Sjuksförsäkring*).
9. **Norway:** In Norway, CHD is recognized as a disability and the patient is provided with a Disability Pension (*Uförsäkring*).
10. **Denmark:** In Denmark, CHD is recognized as a disability and the patient is provided with a Disability Pension (*Sygdförsäkring*).

India is a country that is a member of the United Nations, and when we talk about rights here, the government should recognize those people who are congenital heart defect patients and are fighting this disease. The government should recognize their disability and give them equality and respect in society and provide all their rights.

Most kids with CHD need the first heart surgery when the heart is of the size of a walnut.

Prevention of Congenital heart disease and Heart Failure in Children:



Dr. Smita Mishra
Manipal Hospital,
Dwarka, New Delhi

Heart Failure (HF) is a clinical syndrome characterized by the inability of the heart to meet metabolic demands of the body. This inefficient heart then tries to compensate and the patient feels easy fatigability, has high heart rate and respiratory rate. A small baby often has feeding difficulty and falls in the “suck and rest cycle”. He (or she) will have perspiration and will not grow as is required. For example, a baby in the first few months grows by 20-40 grams per day and shows a rising graph in the growth chart.

This incremental weight gain fails to happen. The presentation of pediatric HF is diverse because of numerous underlying etiologies. Consequently, traditional preventive strategies adapted for adult HF cannot be imitated for HF in children.

Prevention Heart Failure, Risks and interventions:

Preventing the heart disease and heart failure (Primary, secondary and tertiary prevention):

Majority of cases with pediatric HF are secondary to congenital structural heart diseases with scarcely any modifiable factors. Therefore, timely identification of HF and its appropriate treatment (secondary prevention) or rehabilitation program of diseases which can not be modified with intervention (tertiary prevention), are the methods to give a better life to pediatric patients.

1. Avoidance of Radiation, Fetotoxic and teratogenic effects of drug, infections, malnutrition and hyperglycemia: Particularly in the first 8-10 weeks of gestation care must be taken and metabolic disease like diabetes melitus must be identified and treated. Antiepileptic drugs like eptoin, warfarin (daily dose of >5 mg), contraceptives, lithium, coffee, alcohol, cocaine, high HbA1c are incriminated as the predisposing factors for congenital heart disease (CHD).
2. Hyperhomocysteinaemia, low levels of methionine and deficiency of Vitamin B2, B6, B12, and folic acid in mothers have a cause and effect relationship with CHD and must be identified early during pregnancy.
3. Fetal stress leads to growth retardation. Now it has been recognized that fetal stress in any form also leads to resetting of metabolic processes and predisposes the fetus for adult onset lifestyle diseases.
4. Maternal overnutrition: and CVD::The maternal diet-induced obesity independently caused programmed cardiac dysfunction, left ventricular hypertrophy in babies.
5. CHD and consanguinity: Consanguinity predisposes a baby to have duplication of recessive genes and causing multiple problems that include congenital heart defects.

Heart Failure in different type of cardiac diseases:

Congenital heart diseases: The prevalence of CHD is roughly, 6-8/1000 live births in various studies. Due to the increasing number of successful interventions for CHD per year, the size of the population of patients with grown-up congenital heart disease (GUCH) is expanding. The severity of symptoms and onset of HF vary according to the type of defect. CHDs are classified as cyanotic and acyanotic heart diseases.

Acyanotic Heart Diseases (*Pulse oximeter saturation SPO₂>95%*): Acyanotic heart defects may be a shunt lesion like atrial, ventricular septal defects, AP window and patent ductus arteriosus. The outflow obstructions like pulmonary stenosis, aortic stenosis and coarctation are also acyanotic lesion. Usually, they are simple defect and can treated with single intervention. However, untreated ASD (11%), VSD & PDA (50-55%) have potential to have severe pulmonary hypertension and catastrophically become inoperable and cyanotic for ever (Eisenmenger syndrome). Anomalous origin of the coronary artery from the pulmonary artery is also an acyanotic heart disease that mimics dilated cardiomyopathy in infants.

Cyanotic Congenital Heart Disease (*Pulse Oximeter SPO₂ <95%*): The babies with CCHD have central cyanosis and hypoxia. WHO, the American Academy of Pediatrics, and IAP, recommend the use of a pulse oximeter in all 4 limbs of a neonate after the 12-24 hours of birth. These babies may have severe hypoxia persistently within few hours after birth (Transposition of great arteries, pulmonary atresia), or Hypoxia and heart failure (D-TGA, Truncus arteriosus TAPVC etc) , or cyanotic spell (Tetralogy of Fallot or TOF physiology).

Appropriate Investigations:

Firstly, anthropometry is done to have baseline information. These measurements are important to know nutritional status, cachexia associated with illness and for customizing the drug therapy. Vitals like heart and respiratory rate, blood pressure followed by clinical examination, also needs to be checked. For parents it is utmost important that they provide detailed history and relevant documents. Patient would be advised a set of investigations and relevant questions may be asked from doctors about the necessity. The routine investigations for a system check like complete blood counts, renal function tests and additionally biomarkers like NT Pro BNP. HF may have effects on other systems. ECG, X-ray chest and echocardiography are the main cardiac related tests. Additional imaging modalities like CT pulmonary angiogram or cardiac cath might be advised. Genetic testing and family screening for genetic diseases are important preventive measures.

Management plan: Management plan for a congenital heart disease depends on the diagnosis.

Acyanotic Heart Disease: Acyanotic heart defects may not create any hemodynamic effect (like small ASD or VSD or mild AS or PS). These babies are put on echo evaluation at 1-2 years of interval. If heart size is increased or lung pressure is high, then intervention is needed. On an average systolic systemic blood pressure in children varies between 90-100mmHG. While lung pressure is <30 mmHg.

Atrial septal defects: Usually all kind of isolated ASDs, take time to create hemodynamic imbalance and are operated or undergo device closure after the age of two years.

Moderate to large Ventricular septal defects, Aorto-pulmonary window, patent ductus arteriosus: Moderate to small defects may cause cardiac enlargement and high lung pressure. Usually affected child may remain normal till 6-8 weeks. **Subsequently they present with high heart rate, respiratory rate, perspiration poor weight gain and have prolonged breast-feeding time (>20min and show suck and rest cycle).**

These patients may have a short period of false wellbeing after the age 6-8 months. Parents need to remember that a qualified pediatric cardiologist must be guiding them, and they must not fall prey to sudden amelioration of symptoms.

This may be hallmark of rising resistance of lung arteries causing irreversible changes in lungs. After a while these children start showing low SPO₂ on pulse oximeters and then permanent cure may be out of reach from medical science.

Timely intervention is also required for lesions like pulmonary stenosis, aortic stenosis and coarctation of aorta. These CHDs, with severe obstruction, lead to high pressure in respective ventricle and may cause heart failure which only can be managed with appropriate balloon or surgical procedure.

Anomalous origin of left coronary artery from pulmonary artery mimics dilated cardiomyopathy but can be corrected by surgery.

Cyanotic heart disease: These CHDs are always complex and have more than one component. Therefore, their management needs intricate evaluation and careful planning. total anomalous pulmonary venous drainage, Classical tetralogy of Fallot and transposition of great arteries may have excellent outcome when treated on time. But may be potentially fatal if not managed on right time.

CHDs like truncus arteriosus, tricuspid atresia or single ventricles, double outlet right ventricle, are complex disorders and usually need staged surgery.

Medical management of CHD related heart failure:

Anemia, Infection as the factors causing Heart failure:

Any stable and hemodynamically insignificant heart disease may decompensate and may cause acute or chronic heart failure. The annual incidence rate of IE is 0.05 and 0.12 cases per 1000 pediatric admissions.

Substrate for the IE usually affects the structurally abnormal heart and can be caused by a wide spectrum of organism which includes virulent and non-virulent bacteria, fungus etc . In presence of IE, the natural history of hemodynamically insignificant HD like small PDA, VSD or bicuspid aortic valve may be affected adversely.

A 14-year-old girl presented with an ejection murmur and was diagnosed to mild aortic stenosis, and she was put on medical follow up. After 6 months she presented with fever for 3 weeks, pedal edema and inability to do routine work. Echo was drastically changed, vegetations were seen attached to AV, leading to severe aortic regurgitation, acute heart failure.

This girl needed to undergo cardiac surgery urgently. She was operated and aortic valve replacement was done to tide over the crisis. Therefore, it is important to be strict in keeping dental hygiene and other measures to prevent any bacteremia.

Anemia can be equally detrimental if hemoglobin falls below 10gm%.

Medical Management:

The drugs like furosemide, digoxin, ACE inhibitors are used to help a patient through HF crisis.

Beta blockers and ivabradine are often used to control heart rate.

Antiarrhythmics are used to control abnormal rhythm in operated and unoperated cases of congenital heart diseases.

Cath and surgical interventions:

Cath procedures like device closure for shunt lesions and ballooning procedure for valvular obstruction are prioritized now a days, in selected cases. Cyanotic CHD needs multiple interventions. A baby born with D-TGA had severe cyanosis after 12 hours of birth and underwent balloon atrial septostomy, and then underwent atrial switch operation at the age of 15 days. Same child needed another surgery at the age on 10 years for supra valvular stenosis, a complication may be seen in 5-10 % cases underwent arterial switch operation.

ECMO, LV assist device and cardiac transplant:

In patients with resistant heart failure ECMO (transient period), LVAD (for bridge therapy) and cardiac transplant (Destination therapy) may be needed.

How to select a destination for your child's heart treatment?



Dr. R Krishna Kumar
Amrita Institute of
Medical Sciences and
Research Centre
Cochin, Kerala

Parents of children with congenital heart defects are often confronted with several challenges as soon as the diagnosis is made and the news is broken to them. One of the most significant of these challenges is to find a reliable institution that can provide comprehensive care that could include surgery, catheter interventions and intensive care. Finding a suitable destination for a child with congenital heart disease perhaps the most important decision that parents have to make. This is largely because there is still considerable variation in the quality of care between individual hospitals.

There is also a substantial difference in costs among these hospitals. Unlike in some countries such as the United Kingdom, it is not mandated in India that individual hospitals share their results openly in the public domain. It therefore becomes difficult for an individual parent to find out how good the results are for specific heart operations. Often, parents also have logistic challenges in that they may find it difficult to travel to far off places for their child's surgery. However, local convenience may not always translate into reliable outcomes.

This brief article outlines important considerations that can serve as a guide to parents of children with congenital heart disease in identifying a suitable destination for treatment. A very basic requirement for any hospital is accreditation by the National Accreditation Board for Hospitals (NABH). But this accreditation quite general and is not specific for pediatric cardiac care.

Before listing out the key considerations for selection of institutions, it is important also to be aware of certain common pitfalls that commonly misguide parents.

1. Do not base judgements on isolated media reports that come out of individual institutions describing successful operations or procedures. Often these are shared with the press for the sake of publicity. These reports do not present the entire picture for the given institution. A common example is reporting a successful heart transplant operation. A single successful heart transplant operation conveys very little about the capability of the institution to do other specific cardiac surgeries.
2. Internet searches on given hospitals or doctors, also do not provide an accurate assessment of the institution's capabilities. Information in the internet is essentially unfiltered and tends to often provide a distorted picture.
3. Do not base your judgement on other services provided by the hospital. For example, having a good adult cardiology and cardiac surgery facility with capabilities of doing advanced heart operations in adult does not necessarily translate into paediatric cardiac expertise.
4. Do not base your judgement on the presence of one or two highly famous superstar cardiologists, or surgeons in a given institution. It is the team that matters much more than individuals.

A Checklist for Parents:

Below is a 10-item checklist that could serve as a useful guide to parents in identifying a suitable destination for their child's cardiac care. I acknowledge that it is not necessarily easy for the parents to obtain specific insights into each of these items.

1. **High level of skill among caregivers:** Taking care of children requires high-level of skills in distinct disciplines that include Pediatric cardiac surgery, Pediatric cardiology and Pediatric cardiac Anesthesiology/ intensive care. There is also requirement for other skilled personnel that include nurses, perfusion, technologists and respiratory therapists. The role of a Paediatric Cardiologist is in making an accurate diagnosis and planning the surgery.

Some conditions can be managed by the cardiologist through catheter interventions. However, even for those conditions that can be managed in the catheter lab, it is always useful to have surgical back up in the rare event that there is a complication. While visiting program for the first time, it is quite reasonable for you to enquire about the members of the team.

2. Cohesive teamwork: It is not enough just to have individuals with skills. These individuals have to work together cohesively. One way of knowing that the hospital has well-coordinated and cohesive team is to determine whether the team has been working together over reasonable period of time. Cohesive teamwork is perhaps the most critical component of a successful paediatric heart program.

3. Quality Infrastructure & equipment: While many hospitals advertise and display that they may have the most recent equipment and facilities such as robotic surgery, the truth is that the most advanced technology does not necessarily translate into safe outcomes. While the hospitals should have updated and well-functioning equipment, it is not the most critical aspect of a paediatric heart program. To a substantial extent, individuals matter much more than machines and equipment

4. Constant focus on quality improvement- Pediatric heart programs that have a conscious focus on quality improvement are likely to deliver the best results. Often such programmes voluntarily share their results in multi-institutional collaborative networks. One example of such a program is the quality improvement collaboration for congenital heart disease (IQIC). Pediatric heart teams have a strong focus on quality improvement, also, invest a great deal in Infection control and quality of their nursing.

5. A system for charitable care: Pediatric heart operations and catheter procedures are expensive. Many families are significantly challenged when they have to generate the entire costs out of their own pocket. Many insurance companies still do not provide cover for congenital heart care. If you are likely to be financially challenged, you must look for hospitals that work with funding agencies and philanthropic organisations to find ways to help parents overcome this financial challenge.

6. Evidence of a Strong Ethical framework: It is generally challenging to determine whether or not a hospital has a strong ethical framework. However, many corporate hospitals tend to compensate physicians or surgeons based on the number of procedures they perform. This can lower the threshold to do procedures. This is particularly true for catheter-based procedures. For example, a small ventricular septal defect (VSD) in many instances does not need closure, but catheter closure may be offered just because it's possible. This is extremely controversial area, but in circumstances where your child is completely well and the defect is small, it is always good to get a second opinion if a procedure is being recommended.

7. Support from other pediatrics specialties: Pediatric heart disease often does not manifest in isolation. Other organ systems may also be affected or your child may have a genetic or developmental issue that merits attention from other Pediatric specialists. In general, the quality of care is better and more comprehensive in Pediatric heart programmes that are located in large multispecialty hospitals that are supported by other pediatric specialities.

8. Other support systems such as social workers: Support staff, such as social workers, play a very significant role in enabling care and serving as a liaison with funding agencies. Departments with a strong presence of medical social workers can help ease the parental anxiety and help secure funding assistance from philanthropic organisations.

9. Communications: Like in other areas, the promptness of responses and quality of communication from a department are a good indicator of their professionalism.

10. Word of Mouth - Experiences of previous patients: Once you have identified or shortlisted a potential destination for your child, it's always useful to speak to other parents about their experiences with heart surgery, or other procedures in the place that you are considering. You can run the individual aspects of this checklist with them.

To Live With A CHD - Social And Emotional Aspects



Dr. Sejal Shah
Hands on Heart
Bangalore

The day, you found out about the heart disease (for yourself or your child), would be distinctly remembered, and that too, as the day that changed your life. It must have been a day, filled with worries, anxieties and self-doubts.

Congenital heart disease is one of the most common congenital defects seen. It usually gets diagnosed at a younger age, however sometimes during adolescence and many a times in fetal life. The diagnosis may make you feel scared

with uncertainty gripping you. You feel it appears to have affected only you (and your family) while rest of the world is completely normal. Anger, resentment and fear are common emotions at that time. This may be followed by questions like “Why me?” and a feeling of being different.

The experts in general will guide you on various aspects of the congenital heart disease. They would have a detailed discussion about the diagnosis, the subsequent plan which may include specific procedures to be done, the ideal timing of procedure, risks associated with the procedure, medical management, follow up plan and so on. However, a congenital heart disease is a life changing situation which may affect the child and the family in many more ways, that are commonly overlooked in a hospital setting especially in India.

Let us try to understand how the diagnosis of heart disease in a child impacts the child and the family. There are few factors which can decide how a child feels.

1. **Age of the child at the time of diagnosis:** Challenges of a diagnosis at a younger age are different compared to an adolescent. For a young child, pain and separation from parents during hospitalization, procedures are major concerns. For a teenager, to have a heart disease and to take medicines, undergo procedure and have a scar, not able to indulge in activities like his / her peers is an emotional struggle. Sometimes the child feels embarrassed about the cardiac condition. This whole experience may make the child withdrawn and give rise to low self-esteem which may affect their education and social life. As they grow out of adolescence, with more understanding about life in general, their worries about future personal and professional life sets in.
2. **Type of heart disease:** Complex heart diseases may affect the quality of life. Having low oxygen levels for a long time may add to lack of feeling of well-being and anger outbursts. The ability to be physically active may be limited. Multiple surgeries and being in and out of the hospital, physical pain and emotional isolation may have an impact on the child. Taking medicines and regular blood tests also may make the child feel not normal. Adults with heart diseases and undergoing staged interventions may feel that all is not behind them. They may feel fearful about declining health.
3. **Body habitus:** Color of the nails and eyes, scars on the body and a different physical habitus (tall or short, skinny) can at times have an impact on their ability to be like their peers.
4. **Personality of the child:** The personality of the child will also decide how soon the child can accept challenges, fight the adversities and bounce back to normal. Some children are more anxious than others and the whole experience of hospital visits and admissions, being away from home and meeting strangers may have a greater negative impact on them.
5. **Miscellaneous factors:** Personality of the parents: The way parents cope up with the situation will have a direct impact on the child's coping capacity. Openness of parents to the outside world regarding the child's condition may be taken in different ways. Sharing the child's heart disease and their journey to the outside world either in person or by writing about their condition may not be liked by many children.

Communication between parents and the child: Some parents decide not to disclose the real facts about the disease to the child for fear of hurting the child. Unfortunately, this may have a negative impact on the child over years in developing a trustful relationship with parents. Openness in the family will make the child more comfortable to ask doubts about the disease. Discussing with doctors about getting a plastic surgery to remove the scar may make the child feel embarrassed and create self-doubts.

Financial status: Family may go through more difficult times due to their financial status leading to delay in timely management and prolongation of symptoms in the child.

Non-cardiac concerns: At times, congenital heart disease in the child may be accompanied by other issues such as learning disabilities in the child which further makes it difficult to navigate their daily life.

Sibling: Presence of a sibling may also have an impact. Comparison done with a sibling by parents or even by self, may cause jealousy and low self-esteem. A supportive and understanding sibling can be of help to the child and the parents.

Now, let us see how do we navigate this journey. We do not want “Congenital heart disease” to define the child more than it does. Child is still a child. Treat the child as normal as possible. It is important to acknowledge the presence of the heart disease, but to define a boundary. To maintain a delicate balance by not underdoing or overdoing has to be learnt. To consciously understand this and self-correcting while dealing with the child could lead to better days.

1. Validate child's feelings:

- It is common for children to feel fearful, not only about pain, but also about their health and future. Explain to the child about the heart condition in an age appropriate manner. Listening to their thoughts and how they feel is important. Communicate with children to understand their perspective. Recognize child's stresses and support them. Any negative feeling should not stay ingrained in them. A difficult question from the child may be answered later but not avoided. Any inaccurate beliefs should be corrected.

- Prior to any procedure, communication with the child will help them be mentally prepared for the intervention. Being truthful will help the child gain confidence in parents and over time the bonding between the child and parents would grow stronger. The child need not be explained everything what the parents have understood, but it can be simplified based on the age of the child.
- Limitations in physical activity may cause a sense of disappointment especially in teenagers which needs to be handled patiently, with the help of the treating physician. Lot of times, adolescents do not like to be told frequently about their disease in presence of other children, hence this needs to be handled in a sensitive way.
- Try not to sympathize with them and make them feel weak. Create clear boundaries early in childhood so that they understand how to conduct themselves. Try to help them build their self esteem by counseling, participating in some permissible physical activity, developing hobbies and having social connections. School absenteeism need to be practically looked into and supported by parents.
- Children have a right for privacy, and that should be respected.

2. Parents' health:

- Parents' good health is crucial for facing the demands and challenges of a child with complex congenital heart disease. It is imperative to inculcate healthy lifestyle and mechanisms to cope with physically and emotional distress. Parents should find time to relax.
- Parents' strength, patience and resilience helps their child to acquire similar qualities. It is crucial to maintain a positive outlook and have patience by surrounding yourself with positive people and involving in activities such as meditation and yoga.
- Another important aspect of parenting a child with heart disease is to "Ask for help".
 1. The best help can be obtained from other parents who have children with heart disease. Form support group, however small it may be. A support group would help in exchanges of ideas, share worries and experiences and arrive at solutions. Advice from parents for parents is the best.
 2. Try to have support system for logistics, in terms of a family member or an external aid.

- To have a clear understanding about the disease and the future management, discussing with the treating physician could help parents have a clearer vision. Try not to have “what if?” to avoid unnecessary anxieties.
- As a parent, keep a check of your expectations for the child, be practical, both medically and non-medically (e.g. academics). Try not to compare the child with other children in terms of body habitus or achievements. Do not expect the relatives and neighbors to understand what you are going through, you may also not be able to empathize them.
- Enjoy small milestones in life and find a reason to rejoice. Gratitude count would be a good way to stay positive.
- Many parents feel overwhelmed and seek support. They would want to connect to others to validate their trauma. This would be true especially in the early days after the diagnosis and when the child is young. There is a strong temptation to share the details of the child either in person or online. It would be better to pause and think if the child when old would be comfortable to the fact that his / her details were shared.

The life of other people outside may look perfect, but other children and parents may have struggles that we are unaware of. Mental health problems, behavioral problems are otherwise there in general population, and hence, how much is contributed by congenital heart disease / treatment may at times be difficult to define. Many times, congenital heart disease may change the outlook to life. You may start appreciating little things in life, change priorities and be more compassionate. Let us all put an effort to help ourselves where ever possible and let the congenital heart disease not define us.

CHDs are the most common cause of infant mortality due to birth defects.

The Hidden Risk : Long-term Arrhythmias in CHD



Dr. Atul Prabhu
Narayana Health
Bangalore

Congenital heart disease (CHD) affects thousands of children born every year. While surgical advancements have significantly improved survival rates, a lesser-known complication can arise years after surgery: long-term arrhythmias. In this article, we'll explore what arrhythmias are, why they occur in CHD patients, and what can be done to manage them.

What are Arrhythmias?

An arrhythmia is an abnormal heartbeat rhythm. It can be too fast, too slow, or irregular. Imagine your heart beating like a drum; in arrhythmia, the drumbeat becomes irregular, affecting blood flow and overall health.

Why do Arrhythmias Occur in CHD Patients?

Surgery for CHD can sometimes disrupt the heart's natural electrical pathways, leading to arrhythmias. Additionally, the heart's structure and function may be altered, increasing the risk of abnormal heart rhythms. Other factors, such as age, genetics, and underlying medical conditions, can also contribute to arrhythmias.

Incidence of Arrhythmias in Post-Operative CHD Patients

Studies have shown that:

- 25-50% of CHD patients develop arrhythmias after surgery (Source: American Heart Association)
- The incidence of arrhythmias increases with age, with 60-70% of CHD patients developing arrhythmias by adulthood (Source: *Journal of the American College of Cardiology*)

- - Atrial fibrillation (AFib) is the most common type of arrhythmia in CHD patients, affecting up to 30% of patients (*Source: Circulation*)

Types of Arrhythmias in CHD Patients

There are several types of arrhythmias that can occur in CHD patients, including:

1. Atrial Fibrillation (AFib): A fast, irregular heartbeat that can increase the risk of stroke and heart failure.
2. Ventricular Tachycardia (VT): A fast, abnormal heartbeat originating in the ventricles, which can be life-threatening if left untreated.
3. Atrioventricular Block (AV Block): A delay or blockage in the electrical signals between the heart's chambers, which can cause symptoms like fatigue, dizziness, and shortness of breath.

Symptoms and Diagnosis

Arrhythmias can be asymptomatic or cause symptoms like:

- Palpitations
- Chest discomfort or feeling tightness
- Shortness of breath
- Dizziness
- Chest pain

Diagnosis involves:

1. Electrocardiogram (ECG): A non-invasive test that records the heart's electrical activity.
2. Holter Monitoring: A portable device that records the heart's activity over 24-48 hours.

Management and Treatment

Treatment options vary depending on the type and severity of the arrhythmia. These may include:

- Medications: To regulate heart rhythm, control symptoms, and prevent complications.
- Catheter Ablation: A minimally invasive procedure that uses heat or cold energy to destroy abnormal electrical pathways.
- Pacemakers or Implantable Cardioverter-Defibrillators (ICDs): Devices that regulate heart rhythm and prevent life-threatening arrhythmias.

- **Lifestyle Modifications:** Such as exercise, stress reduction, and a healthy diet, which can help manage symptoms and prevent arrhythmias.

Why Early Detection Matters

Early detection and treatment of arrhythmias are crucial to prevent complications and improve quality of life. Untreated and undiagnosed long term arrhythmias can lead to a condition called “Tachycardia induced cardiomyopathy “ which results in weakening of heart muscles and poor ejection.

CHD patients should:

1. **Regularly Monitor Their Heart Rhythm_:** Using a pulse monitor or ECG.
2. **Report Any Symptoms:** To their cardiologist or primary care physician.
3. **Attend Regular Follow-Up Appointments_:** To monitor their condition and adjust treatment plans as needed.

Long-term arrhythmias are a potential complication for CHD patients after surgery. While they can be asymptomatic, it's essential to be aware of the risks and symptoms. By understanding arrhythmias and seeking medical attention when needed, CHD patients can lead active, healthy lives.

Resources:

- *American Heart Association. (2017). Arrhythmias in Children.*
- *Journal of the American College of Cardiology. (2018). Arrhythmias*
- *Pediatric Cardiac Society of India (PCSI)*

If you're a CHD patient or caregiver, don't hesitate to reach out to your healthcare provider if you have any concerns or questions about arrhythmias. Early detection and treatment can make a significant difference in managing this condition and improving quality of life.

Conversation with Dr. Swati Garekar

CHD (Congenital Heart Defect) is the most common birth defect in all over the world. Roughly in every hundred newborns there is one with CHD. In India over 2 Lac CHD kids are born every year. Of these one fifth are likely to be requiring surgery in the first year of life.

Dr. Swati Garekar is a renowned paediatric cardiologist in Fortis Hospital, Mumbai. She is actively working for CHD awareness. Through social media platforms she is sharing informative videos for public. Here is a conversation of a CHD mother Jonali Choudhury with Dr. Swati Garekar about many things related to Congenital Heart Defect.



Dr. Swati Garekar
Fortis Hospital
Mumbai

Jonali Choudhury - "Good morning ma'am.

My first query is what is the exact total of Indians with CHD at present? What is the ratio of adults and children?"

Dr. Swati Garekar - "I don't have the exact number of children with CHD in India. I can tell you that about 1 out of every 100 new-borns have a CHD. Most of them will need some kind of intervention for CHD. There are far more children with CHD compared to adults with CHD in India. The ratio is opposite in the USA."

Jonali Choudhury - "What is the reason of this difference?

1. In India it was not possible to reach adulthood with CHD
2. Those adults who might have had CHD were not diagnosed to be CHD patients.
3. In India CHD is not diagnosed before birth."

Dr. Swati Garekar - "The percentage of patients who were operated and are now adults is less compared to the child patients in India. In the US, where they have been operating since 1950s, they have a much higher number of adults with operated CHD. The demographics of the population in US and in India is also different: India has a huge number of people in the child bearing age group so a lot of newborns in India..."

Jonali Choudhury - "OK ma'am. The next question is What are the CHDs which do not need interventions? When do you (all paediatric cardiologists) suggest a CHD patient medical management? Is it like - They don't need surgery OR They can't have surgery?"

Dr. Swati Garekar - "The CHDs which don't need surgery or cath intervention are those small ASDs where heart size is normal; mild pulmonary stenosis; bicuspid aortic valve with no significant stenosis or regurgitation; tiny PDA that is not associated with a murmur; mild mitral regurgitation that is non progressive. We suggest follow up with no restriction in diet or activity; serial follow up is a must. It may once in a year or 2 years or 3 years etc. We say : They don't need intervention at the present time. In the future, there may be change in the heart condition that may need an intervention OR there may be a new kind of treatment available where risk /benefit ratio is favourable to intervene even though it is a small CHD."

Jonali Choudhury - "Got it ma'am. My next question is - Which CHDs are more common? Are the common CHDs less severe? Is there any particular CHD that is more frequently seen in India?"

Dr.. Swati Garekar - "Common CHDs are ASD, VSD, PDA, Pulmonary stenosis, Tetralogy of Fallot, Coarctation of Aorta.

ASD, VSD, PDA are less severe.

We see a lot of everything in India!"

Jonali Choudhury - "OK. Ma'am - What is the cause of CHD? Is it completely unknown? Or you - the medical people guess some causes but don't say it because it is not properly established?"

Dr. Swati Garekar - "Not established for most CHDs.

We call the cause " multifactorial".

Sometimes we find a cause like a Genetic mutation.

When couples ask me about the chance of having a baby with a CHD in their next pregnancy, I tell them the chances of having a normal baby are very high. But there is nothing they can do different to ensure that the foetus will have a normal heart,

other than normal healthy living: healthy food clean air clean water clean soil, no occupational hazard pf exposure to toxic chemicals in the first 3months of pregnancy. The couple can take multivitamin capsules from the time of planning a baby.

If the prior foetus/baby had genetic a mutation, then the parents can get tested to see if one of them is carrying the mutation. Further, in the next pregnancy, the fetus can be tested for the same mutation. .

Couples have an option not to continue pregnancy in case of a very major chd, if it is detected early enough (as per Govt rules)."

Jonali Choudhury - "So in short CHD is inevitable? Because healthy lifestyle is good for everyone. Previous generations' lifestyle was healthier than ours. Did CHD occur less in the past? (Diagnosed cases might be less, I guess, not sure though)"

Dr. Swati Garekar - "Yes, which fetus will have a CHD is hard to predict. In certain situations, CHD is more likely to occur: for eg: fetuses with mother with pre existing diabetes, mother taking certain medications, IVF pregnancy, family history of CHD, mother with certain auto-immune diseases. CHD is also more likely if fetal early scan shows NT >3.5mm or if some other organ system of the fetus is abnormal.

Yes, diagnosis was less because there was less availability of echo machines and pediatric cardiologists; so less children with CHD were detected.,

Pollution (of all kinds- what we breathe, eat, touch) was less."

Jonali Choudhury - "So has CHD cases increased? How do you see Indian CHD population in future? Will it increase exponentially? Or with the advancement of medical science it will stay constant? Any possibility of reduction?"

Dr. Swati Garekar - "Yes CHD cases have increased in India primarily as there is more detection due to better awareness amongst doctors and better availability of echo machines and paediatric cardiologists. I suspect the population will stabilize. Look at the West: there the population of very very complex CHDs is declining as couple choose not to continue pregnancy when foetus is diagnosed with them."

Jonali Choudhury - "Hope Indian parents will also become rational. - Do you think foetal echo should be advised to all irrespective of whether they have or not family history of CHD or irrespective of risk factors of CHD? Because many CHD parents are without any family history of CHD."

Dr. Swati Garekar - "No. Only for the standard indications. You are right. Very few have family history."

Jonali Choudhury - "What do you want to tell the parents whose kid's CHD is just diagnosed? And to the parents whose kid has already undergone surgery? Is there something you want to advise them to follow religiously?"

Dr. Swati Garekar - "For the parents whose baby is just diagnosed with CHD, I want to tell them to make sure to consult a paediatric cardiologist and to be treated where there is a TEAM of doctors taking care of their baby. I want to tell them if they don't believe what is being said to them, they should take a 2nd opinion BUT ONLY from another paediatric cardiologist. I want to then tell them, that if treated on time, the baby has a good chance of doing well! And to the parents whose kid has already undergone surgery, I want to tell that please keep a follow up with your paediatric cardiologist as when instructed. Also , there is no room for restriction in diet or activity for most children with repaired CHD."

Jonali Choudhury - "OK. Ma'am, how many families of your patients come for follow up regularly? Have you seen someone from infancy to adulthood? How does it feel to see them grow?"

Dr. Swati Garekar - "Many. Yes, I have seen such patients. It feels awesome! I somehow remember all details of the child."

Jonali Choudhury - "I can imagine the feeling!

Does India have a proper set up for taking care of the adults with CHD? Does your hospital have a well equipped branch for the adult CHDers? Which hospital in India is best for them?

Also Is Indian society capable of accepting and respecting the adult CHDers?"

Dr. Swati Garekar - "Yes, units in India where adult and paediatric cardiac teams work alongside each other can and do take care of adults with chd.

Yes, our hospital can take care of adult repaired and unrepaired chd

Indian society? The CHDer cannot afford to worry about what it thinks.

The CHDer has multiple challenges from getting insurance to getting employed to getting married and beyond."

Jonali Choudhury - "Can we be optimistic about the future of adult CHDers without insurance and without dignified employment? Your advice for the adult CHDers?"

Dr. Swati Garekar - "Yes... To optimism...

It is not all gloom and doom.

On paper, CHD is supposed to be covered by insurance.... Hopefully one day it will be carried out in reality too

One should keep savings aside for medical emergency

And make sure to have insurance for non chd related illness

My advice: connect on social media...form groups... Help each other...And there is always hope ... for any problem that comes up"

Jonali Choudhury - "Insurance companies don't cover non cardiac issues of a CHDer. They don't accept the proposal, neither they answer in writing. I have tried many times."

Dr. Swati Garekar - "That is so sad. I know my patients have also had to struggle."

Jonali Choudhury - "My next question is - Which CHDs need multiple surgeries? Is there some CHD which need no further care after the surgery?"

Dr. Swati Garekar - "There are a few CHDs which need multiple surgeries, for example

Single ventricle anatomy

TOF with pulmonary atresia

Truncus arteriosus

Shone complex

There are some other chds where complications can happen overtime, after complete repair. But it is not a hundred percent that another surgery will be required For example

-Complex TGA

-Complex DORV

There are few isolated chds where no further care is required after surgery, like

-PDA

-ASD

-Pulmonary stenosis

- Most isolated VSDs

Even then I would prefer following such patients up once in a while."

Jonali Choudhury - "Ma'am, Which CHD patients are at risk of developing pulmonary hypertension? Can it be prevented?"

Dr. Swati Garekar - "Children with large VSDs or PDAs are born with pulmonary hypertension. If corrected in time, the condition resolves after closure. If uncorrected, the PH hardens the pulmonary vessels and causes pulmonary vascular obstructive disease.

Correcting the CHD in time is the best way to prevent pulmonary vascular obstructive disease.

The other causes of PH are TGA with VSD or DORV or AP window or Truncus arteriosus or certain types of complex heart defects like Hypoplastic left heart syndrome, single ventricle etc."

Jonali Choudhury - "Which CHD patients might need a heart transplant and which are likely to need heart lung transplant? Will a single ventricle patient need it sooner or later?"

Dr. Swati Garekar - "Certain CHDs are more likely to need a heart transplant: ccTGA or LTGA with failing right ventricle is most common.

Another set is Fontan failure or TOF after repair or very complex CHD like Shone complex.

Eisenmenger syndrome or TOF with pulmonary atresia with MAPCAs will need heart and lung transplant."

Jonali Choudhury - "What are the risks of something happening suddenly to a CHDer? Is regular follow up sufficient to prevent such accident?

Can we prevent arrhythmia, heart failure or blood clots in the CHDs?"

Dr. Swati Garekar - "The risk of sudden cardiac death (averted or not) varies depending on the type of CHD. The risk is certainly higher than the general population.

Certain CHDs repairs like Senning or TOF are more prone to arrhythmias.

Regular follow up which includes appropriate testing like Holter, exercise stress test or cath, other than routine echo ECG and consultation is essential.

Heart failure : to give a chance to prevent it, means to pick it up and treat it early. For that routine follow up is essential.

Blood clots are more likely in a patient with Fontan circulation . They are placed on anti platelet agents or blood thinners to prevent clots."

Jonali Choudhury - "Ma'am, parents need some information about CHD care centres in India. We need to know which centre is best for the procedure our kid is going to have. We need to know which centre is best in making the decision or which one is best for post operative care or post operative complications. Is it possible to get these data? Is it impossible to get these data?"

Dr. Swati Garekar - "I think parents should have a list of centres divided region wise

along with list of senior doctors there.

There is no public data that is shared on outcomes."

Jonali Choudhury - "One parent asked this - What's the prognosis of one and a half ventricles? Or going for single ventricle is better?"

Dr. Swati Garekar - "1.5 ventricle is a better option than Fontan for the carefully chosen patient."

Jonali Choudhury - "Ma'am, another parent asked - How doctors are deciding when to go for Fontan ?"

Dr. Swati Garekar - "For an extracardiac conduit kind of Fontan completion surgery , the weight should be 14-15 kg. The typical Indian child achieves this weight at age 4-5 yrs."

Jonali Choudhury - "Ma'am another parent asked this regarding 8-year-old kid, who has been diagnosed with cctGA and is completely asymptomatic. The parent has contacted multiple doctors and received differing opinions. Some suggest proceeding with PA banding along with a pacemaker, while others recommend regular follow-ups without intervention.

The parent is unsure whether PA banding is absolutely necessary or if they can continue with regular monitoring. Additionally, the parent would like to know if there are any emerging technologies or ongoing research that might offer better solutions for this condition in the future."

Dr. Swati Garekar - "I need to see the echo report to opine.. The status of the tricuspid valve and the RV are important factors to consider in a case like this 8 yr olds'."

Jonali Choudhury -" So we are at the end of the conversation. Thank you ma'am. From your busy schedule you have spared so much time for this. As the concluding remark would you like to advise something to the CHD parents and the adult CHDers? Also would you like to tell the healthy non-CHD population something about CHD?"

Dr. Swati Garekar - "For CHD parents and adult CHDer: For most situations you face: Never ever ever let anyone tell you that there is no hope. Always keep in touch with your heart care team. Maintain your file properly and keep softcopy on your phone too.

For non CHD population: people with CHD are as healthy as you are....

They can eat whatever you can. They can play as much as anyone else can.

.. They have overcome a disease in the best possible way available to them ..."

Jonali Choudhury - "I know saying thank you is not enough, but that is what I can do to express my gratitude. Thank you so much ma'am."

Where The Mind Is Without Fear: *The CHD* *version*



Dr. Debasis Das
Narayana Superspeciality Hospital
Howrah



*Where the mind is without doubt and the head is held proud,
Where training is proper and infrastructure complete,
Where the world has not been broken up into fragments
By narrow economic categories of patients,
Where words come out from the depth of true databases,
Where tireless striving stretches its arms towards making it accessible to all,
Where the clear stream of reason has not lost its way
Into the rampant misuse of antibiotics,
Where the mind is led forward by thee
Into ever-widening audits and introspection,
Into that heaven of ideal care and outcomes, my Father, let my country awake.*

With Apologies and Deepest regards to Gurudev Rabindranath Tagore



Heart Warriors: The Unseen Strength of Brave Parents

Dr. Priyanka Bameta
(A Proud CHD Mom)
Uttarakhand

Parenthood is often described as a journey of love, patience, and sacrifices. However, for parents of children born with congenital heart defects (CHD), this journey transforms into a heroic battle—a testament to their unwavering strength and resilience. These parents, often referred to as "Heart Warriors," embody a rare courage, fighting battles most of us can't imagine while shielding their children with unyielding love and determination.

The First Battle: Diagnosis

For most Heart Warrior parents, the battle begins with an unexpected diagnosis. The words "congenital heart defect" can shatter dreams and instill fear, but these parents don't give up. They absorb complex medical jargon, make decisions amidst uncertainty, and prepare themselves for a life that revolves around doctor visits, surgeries, and intensive care. Their ability to remain calm and decisive during such turbulent times is nothing short of heroic.

Daily Challenges: A Test of Resilience

The life of a Heart Warrior parent is filled with challenges, both big and small. They become experts at reading medical reports, managing medications, and monitoring oxygen levels. They advocate tirelessly for their child, ensuring access to the best care while balancing the emotional and financial toll that CHD brings. Every meal, every playdate, and every milestone is accompanied by a silent prayer and relentless hope. These

parents must also address their child's emotional and social needs, ensuring they never feel defined by their condition.

A Fortress of Love and Positivity

What makes these parents extraordinary is their ability to create a nurturing environment, despite the storm they face. They become storytellers, turning hospital stays into adventures, and use every ounce of their energy to make their child's world as normal and joyful as possible. Their strength lies in their ability to find hope in small victories—whether it's a successful surgery or a day without complications.

Building a Community of Support

Heart Warrior parents often draw strength from each other. They form support groups, share experiences, and provide a shoulder to lean on for families new to the CHD journey. Their collective strength creates a network of love and resilience that empowers parents and children alike.

Like we do in our group-Heart to Heart, where we are committed to be there for each other.

We teach profound lessons about life: the value of unconditional love, the importance of resilience, and the beauty of finding joy in the smallest moments. They remind us that true strength often comes from the heart—both literally and metaphorically.

Heart Warrior parents don't wear capes or armor, but their courage, love, and determination make them real-life superheroes. They may not seek recognition, but their strength inspires everyone who crosses their path.

To all Heart Warrior parents, we are the unseen strength, the silent heroes who fight not just for your children but for hope, love, and life itself. Your journey is a testament to the power of the human spirit, and your story deserves to be celebrated.

Congenital Heart Defects and Inclusive Growth

Amod Kumar Kushwaha
CHD Father
Mirzapur, Uttar Pradesh

With the world population inching towards 8.0 billion and that of India crossing 1.4 billion, the resolutions of Sustainable Development Goals (SDG) adopted by United Nations in 2016 and SDG 3.2, target to reduce the neonatal mortality to less than 12 per 1000 live births and infant mortality to less than 25 per 1000 live births by 2030. With these objectives of SDG in mind, much is now being talked about the demographic dividends that can be derived from this huge population at global and national level.

Ministry of Health and Family welfare report titled 'Health and Family Welfare Statistics in India 2019-20' attributes 23.3% of total deaths due to cardiovascular diseases, 4% of total deaths in the age group of less than 29 days due to congenital anomalies and 4.6% of the total deaths in the age group of less than one year due to congenital anomalies. According to a rough estimate, of all the babies born with congenital anomalies, 33% suffer from mild to severe form of Congenital Heart Disease (CHD).

The Global Burden of Disease, Injuries and Risk factors (GBD), an international collaboration of researchers, produces internally consistent annual estimates of deaths and disability throughout the world. While the global prevalence of CHD as per the data given by GBD in 2017 estimates 1.8 cases per 100 live births, in India it is estimated to be about 9.14 cases per 1000 live births and roughly 2 lakh cases per year.

Deliberations for any sustainable development, must incorporate in it the policy of inclusion for all sections of citizens. There are certain sections of persons who may be regarded as disadvantaged in terms of access to quality public healthcare and social and financial security. While regulations have been framed for inclusion and empowerment of disabled persons through Persons With Disability (PWD) Act, 1995 revised in 2016 as Rights of Persons with Disability (RPWD) Act, there is a section of population which

remains excluded in the era of Sustainable and Inclusive Growth; these are the persons with congenital heart defects.

While we frequently discuss the discrimination inflicted upon certain communities and persons on the basis of the caste and creed, the inadvertent discrimination and demoralization that the persons with CHD face have rarely been discussed. Most of the patients suffering from CHDs after diagnosis need surgical interventions of complex to very complex nature either in the first four to five years of life, or before they attain the age of 18. Except few specialized government hospitals and some charity hospitals, most of the surgeries are being carried out in private hospitals, requiring huge expenditures on part of parents. The cost of these surgeries in private hospitals goes in lakhs of rupees, which becomes unaffordable for most of the parents belonging to poor socio-economic conditions. PM JAY (Ayushman Bharat Yojna) has definitely benefitted many parents, but looking at the conditions of eligibility for PM JAY and the case load on government hospitals, not everyone gets a chance to get admission in these hospitals, and in cases of extreme emergency parents have to open their pockets wide in the private hospitals or leave the child on his destiny. In both the situations the patients and attendants feel helpless and devastated. While the CHD persons and their attendants fight their battle courageously to get the adequate timely intervention, the factors like the existing healthcare infrastructure, cost of treatment & financial burden, lack of social awareness and stigmatization of CHDs and gender bias discrimination aggravate their problems. The persons with CHD continuously keep struggling with certain associated problems like, low saturation coupled with respiratory and physiological problems, developmental and cognitive problems, like impaired memory, linguistic and speech problems, low attention span and difficulty in concentration, poor planning abilities and poor impulse control. Despite all these complications a child with CHD is expected to compete with his completely normal peer in terms of social, academic and career aspects.

We are at a juncture where, a national policy for the persons with CHD should no more be delayed and the RPWD Act (2016) must be updated with inclusion of CHDs as a disability. The policy document for the CHD people must focus on establishing better CHD care Infrastructure in government sector, Health Insurance Coverage for persons with CHD, lifelong free medical care, alternative academic curriculum for CHD patients with flexible teaching methodology, examination and evaluation pattern and certainty in job opportunities etc. to mention a few from the many urgently required steps to be taken.

Advocating for Your Child in Medical Settings: Managing Fear of the Unknown and Effective Communication with Healthcare Providers

Dr. Suchismita Halder (PhD)
Parent Advocate
Kolkata

Navigating the healthcare system as a parent of a child with medical needs can be overwhelming, especially with unfamiliar medical terminology and complex treatment plans. However, I've been amazed by how parents, myself included, rise to the occasion for their children. The journey often begins with learning about your child's condition—understanding medical terms, treatment options, and potential outcomes. This knowledge empowers you to advocate effectively for your child's care.

Let's explore the key stages of advocacy—from managing the fear of the unknown to fostering strong communication with healthcare providers.

1. Acknowledge and Manage Your Fears

The fear of the unknown can be paralyzing when your child is diagnosed with a medical condition. I've been there—worrying endlessly about what might happen, overwhelmed by complex terms and decisions. It's okay to

feel this way, but I've learned that facing those fears head-on makes a world of difference.

- **Educate Yourself:** I found that learning about my child's condition was the first step to reclaiming some sense of control. Reliable information helped demystify so much and gave me the confidence to ask questions and engage meaningfully with the medical team. However, it is important to not blindly follow everything available online. It's crucial to ensure that the information comes from credible and accurate sources, such as medical journals, trusted health organizations, or guidance from our doctors.
- **Focus on the Present:** One of the best pieces of advice I received was to take things one step at a time. Worrying about the distant future only drained my energy for what mattered right now.
- **Seek Emotional Support:** Talking to other parents who had been through similar journeys or reaching out to a counselor was a lifeline for me. It's comforting to know you're not alone, and there are people who truly understand.

2. Be an Informed and Prepared Advocate

As a parent, I realized I was my child's voice. Being informed and organized helped me communicate better with doctors and advocate for what was best.

- **Document Everything:** I started keeping a detailed file with medical records, test results, prescriptions, and notes from appointments. It's amazing how much easier this made things when talking to different specialists. I maintain two files: one contains all the recent medical prescriptions, which I carry with me at all times, and the other holds detailed documentation about my child's condition and medical history, which I bring along only when necessary.
- **Ask Questions:** I used to worry about asking "too many" questions, but I've learned that no question is ever too small or unimportant when it comes to your child's care. Writing down my questions before appointments ensured that I didn't forget anything at the moment. Over time, I realized that good and experienced doctors encourage caregivers to educate themselves about the condition. They understand that an informed caregiver can make better decisions and collaborate effectively in the treatment process, which ultimately benefits the child. This reassurance gave me the confidence to

ask anything I needed to understand fully.

- **Know Your Rights:** Understanding patient rights and insurance policies is crucial when navigating the healthcare system. Many parents have shared how knowing these details helped them access care and resources they didn't initially realize were available.

3. Build Strong Relationships with Healthcare Providers

Doctors are always so busy and they seem so knowledgeable when they discuss your child's treatment plan. It is natural to feel intimidated at first, but it is essential to understand that you are in the same team, working towards the same goal, my child's well-being.

- **Communicate Clearly and Respectfully:** Sharing observations and concerns openly, but respectfully, built trust with the medical team. I've found that this approach makes doctors more open to collaboration. Respectfully communicating means approaching conversations with a tone of understanding and appreciation for the healthcare provider's expertise. It involves being mindful of their time and knowledge while expressing your concerns, asking questions, or offering input. This approach fosters a constructive dialogue, where both parties feel valued and heard, leading to better cooperation and more effective care for your child.
- **Be Honest:** No one knows your child better than YOU do. Being upfront about symptoms, struggles, and even my own concerns gave doctors the full picture to create the best treatment plan.
- **Partner with the Team:** Once I started seeing healthcare providers as allies rather than authority figures, the dynamic shifted. We became partners, working together for my child.

4. Empower Your Child When Possible

It wasn't easy, but I learned how important it is to involve my child in their care, no matter how small the step. Just like you learning about their medical condition and treatment plan, especially if surgery is coming up, involving them in the process helps them feel empowered and in control.

- **Explain in Simple Terms:** I'd break down what was happening in ways my child could understand. It helped ease their fear and gave them a sense of control.
- **Encourage Expression:** Allowing my child to share their feelings or

even ask questions helped them feel included and more at ease with the process.

I do want to mention, though, that not all children are the same, and it's okay if your child refuses to understand or participate. Do not threaten, scare, scold, or scream at them. Nor should anyone else. This will only traumatize your child. Instead, be on their side, reassure them, and offer comfort and support through the process.

5. Lean on Support Networks

This journey can feel isolating, but I've found incredible strength in connecting with others who understand.

- **Join Parent Advocacy Groups:** Meeting other parents with similar experiences was a game-changer for me. Their advice, shared stories, and encouragement were invaluable.
- **Utilize Advocacy Organizations:** Advocacy groups tailored to my child's condition provided resources, training, and support I didn't even know existed.

Advocating for your child in medical settings requires a combination of emotional resilience, knowledge, and effective communication. By managing your fears, building strong relationships with healthcare providers, and remaining informed, you can ensure your child receives the best possible care. Remember, you are your child's strongest voice and most valuable advocate. Empower yourself, and in doing so, empower your child to face medical challenges with confidence and strength.

CHD is the most common birth defect in
the world.

The Correlation Between Funding and the Lives of Children with CHDs in India

Sajani Nair
Calicut, Kerala

Congenital Heart Defects (CHDs) are the most common birth defects globally and a leading cause of infant mortality. In India, the prevalence is estimated at 8-10 per 1,000 live births, resulting in approximately 180,000-200,000 new CHD cases annually (NIH, PMC). Of these, a significant proportion requires surgical intervention within the first year of life.

Timely and appropriate treatment of CHDs dramatically improves survival and quality of life, but it is extremely cost-intensive, especially for families from economically weaker sections.

The Economic Burden of CHD Treatment

The treatment pathway for CHDs includes screening, diagnosis, surgery, ICU care, medication, and long-term follow-up. These components are often beyond the reach of average Indian families.

- Diagnostics: INR 10,000-50,000
- Surgical Costs: INR 1.5 lakh to INR 8 lakh depending on complexity
- Post-operative care: ICU stays, cardiac medications, and follow-ups incur ongoing costs

For families earning less than INR 20,000/month (common in rural India), these are insurmountable expenses without external funding.

Government Support: A Work in Progress

1. Rashtriya Bal Swasthya Karyakram (RBSK): This central initiative supports CHD children under its '4 Ds' framework-Defects at birth, Diseases, Deficiencies, and Developmental delays.
2. Ayushman Bharat (PM-JAY): Covers INR 5 lakh per family/year. However, according to a Times of India report (April 2025), average hospital empanelment dropped from 316/month in 2024 to just 111/month in 2025. Many private hospitals withdrew due to low reimbursements and delayed payments, impacting CHD access severely.

Role of NGOs: The Unsung Heroes

NGOs play a pivotal role in bridging the care gap for underserved children with CHDs.

Top NGOs Supporting CHD Care in India:

- Genesis Foundation - genesis-foundation.net
- Aishwarya Trust - aishwaryatrust.org
- Needy Heart Foundation - needyheartfoundation.org/
- Healing Little Hearts (India) - healinglittlehearts.org
- Hridayam Initiative (Kerala Model) - hridayam.kerala.gov.in/

Persistent Challenges and Hidden Realities

- Diagnosis Delays: CHDs often go undetected due to limited neonatal screening.
- Urban-Rural Divide: Specialized care is mostly metro-centric.
- Fragmented Funding: Govt schemes, NGOs, and crowdfunding operate in silos.
- Donor Skepticism: Crowdfunding platforms face trust and transparency issues.

The Need for an Integrated Funding Framework

To ensure timely, transparent, and equitable CHD care, India needs a unified digital ecosystem connecting all funding sources.

Proposed Components:

1. Central CHD Registry: Real-time case tracking.
2. Unified Funding Portal: Integrates govt schemes, NGOs, and public donations.
3. Single Window Clearance: Fast-tracks approvals.
4. Public-Private-NGO Collaboration: Ensures reach in smaller cities.
5. Aftercare Support: Post-surgery rehab, nutrition, and medicine funding.

Access to life-saving CHD care in India is deeply dependent on financial support. Though PM-JAY and NGOs have made a positive impact, the system remains fragmented and urban-centric. With private hospitals exiting PM-JAY, the urgency for corrective action intensifies.

India needs a national integrated funding model that synergizes government programs, NGO initiatives, and public support to give every child with a heart defect a genuine chance at life.

There are nearly 40 different CHDs. A child can have a combination of some of those 40.

The Power of a Second Opinion: Parents' Journey Through Complex Congenital Heart Defects

Pritisudha Sharma, Rakesh Bhowmick
(Proud parents of CHD Warrior Rudranshi Bhowmik)
Kolkata

When your child is diagnosed with a complex congenital heart defect (CHD), the world feels like it comes crashing down. You're expected to make life-changing decisions based on frightening medical terminology and often limited options. But one of the most powerful tools any parent can hold onto in such a situation is the courage to seek a second opinion—to question, to explore, and to keep searching for hope when the first answers seem final.

Our Story: When Hope Seemed Like a Risk

Our daughter was born with a large Ventricular Septal Defect (VSD), which functionally gave her a single ventricle, complicated further by severe Pulmonary Arterial Hypertension (PAH). At just 3.5 months old and only 3.3 kg, she was classified as a rare and high-risk case, and most hospitals and cardiologists advised only palliative treatment. The common recommendation was the Fontan pathway—including procedures like pulmonary artery banding, Glenn, and Fontan surgeries. These are not curative but aim to prolong life and improve quality.

At least eight out of ten experts we consulted said Fontan was the only option. Only two even mentioned the possibility of a bi-ventricular repair, and both flagged it as highly risky.

When Doors Seemed to Close

Some hospitals refused surgery outright, citing high mortality risk. We were told she might not survive the operation table, that even a pulmonary artery (PA) banding was too much for her tiny body. But we couldn't give up. We couldn't accept that the only way forward was a path that didn't offer a complete repair, especially without exploring every possible alternative.

The Turning Point: A Second Opinion

That's when seeking more opinions changed everything.

We found a center that didn't just look at her size or textbook risks—they looked at her as an individual, took time to understand her unique case, and were willing to go beyond the conventional.

At 3.5 months, she underwent a PA banding surgery with an estimated 10% risk of mortality. We were told by others she may not make it off the operation table. She was discharged on the 8th day.

Later, at 18 months old, she underwent the highly complex and delicate bi-ventricular repair—the very surgery that had been considered nearly impossible for her by many. The risk? Around 20%, much higher than what most would accept for such a young child. But she made it through. And she was discharged from the hospital in just 14 days. Then, against all prior predictions, she underwent - a true surgical correction rather than palliation.

Why Second Opinions Are Critical in Complex CHD

This experience taught us a powerful truth: not all medical opinions are equal—especially in complex and rare conditions. Many cardiac centers base their recommendations on institutional experience, risk tolerance, and available resources, not always on what might be possible elsewhere. What may be “impossible” in one hospital could be “difficult but doable” in another.

In our case, the Fontan vs. bi-ventricular repair ratio was 8:2, heavily skewed towards the safer, more familiar palliative approach. But we chose the riskier path—not recklessly, but informed, prepared, and prayerful. It wasn't an easy decision. It never is. When we kept searching—despite the denials, the rejections, and the fear—we eventually found a cardiac center willing to take a closer look, ask the hard questions, and consider a different path forward.

A Steep Climb, Step by Step

Like many CHD families, our journey has been anything but easy. From the moment of diagnosis to enduring sleepless nights, feeding difficulties, poor weight gain, and the emotional rollercoaster of decision-making, the toll has been immense. There were days of despair, and moments where everything felt like it was falling apart.

But we kept going. At times, we felt like we were starting from scratch over and over again. The emotional toll was immense, filled with anxiety, breakdowns, and moments of pure exhaustion. But what kept us moving forward was the belief that our daughter deserved every chance—not just the ones offered by default.

We kept asking “Why?”—and more importantly, “Why not?”

Final Reflections

Our daughter’s story is not just about survival—it’s about resilience, faith, and the undeniable importance of seeking more than one voice in the room. If we had listened only to the first few recommendations, we would have gone down a path with no hope of complete repair.

Instead, today, our daughter has a repaired heart—not perfect, but functional, and most importantly, full of possibility. Second opinions can open doors that may otherwise remain closed—doors to alternative surgical strategies, to more aggressive but potentially rewarding approaches, and to centers willing to take on high-risk cases. Of course it is true that facts and figures doesn’t change for all the CHD cases and not all the cases can be measured in same scale. But what we believe is that exploring options doesn’t hurts as much as not giving it a try.

So to every parent out there facing a terrifying CHD diagnosis:

- Ask questions. Get a second, third, or even tenth opinion.
- Don’t be afraid to challenge the status quo.
- Be informed, be brave, and never underestimate the power of prayer, persistence, and hope.
- Because sometimes, the riskier road is the one that leads your child home.

THE PIONNERS WHO MADE THE IMPOSSIBLE 'POSSIBLE'

A brief phtotgraphic history of paediatric cardiology

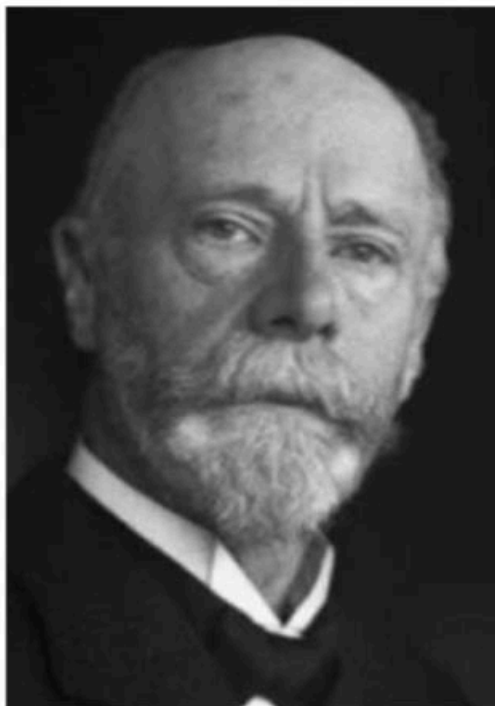
Jonali Choudhury
Guwahati, Assam



In 1628 William Harvey described the pulmonary (heart - lung - heart) and systemic (heart - all other parts of the body - heart) circulation.



In 1671 Nicolas Steno (top) described the cardiac pathology of a stillborn fetus which in 1888 was described in detail by Etienne Louis Arthur Fallot (bottom) and later was termed as Tetralogy of Fallot (TOF).



In 1902 Willem Einthoven invented the practical electrocardiograph (ECG).



In 1936 Maude Abbott illustrated the circulatory diagrams, chest X-ray and electrocardiogram for TOF.



In 1929 Werner Forssmann put himself under local anaesthesia and inserted a catheter into a vein of his own arm. Thus cardiac catheterization was introduced.



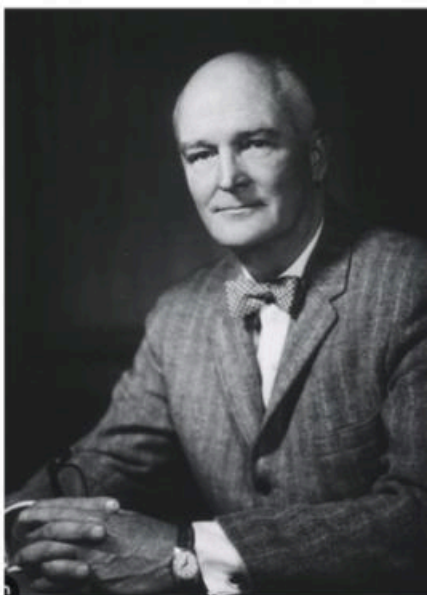
In 1938 Robert Edward Gross did the first PDA ligation.



On 29 th November 1944, Helen Taussig (right), Alfred Blalock (middle) and Vivian Thomas (left) put a shunt in a 15 month old baby with TOF which is now called BTT shunt procedure.



In 1948 Russell Brock operated pulmonary stenosis by transventricular approach.



In 1953, John Heysham Gibbon successfully closed an ASD using a heart lung machine.



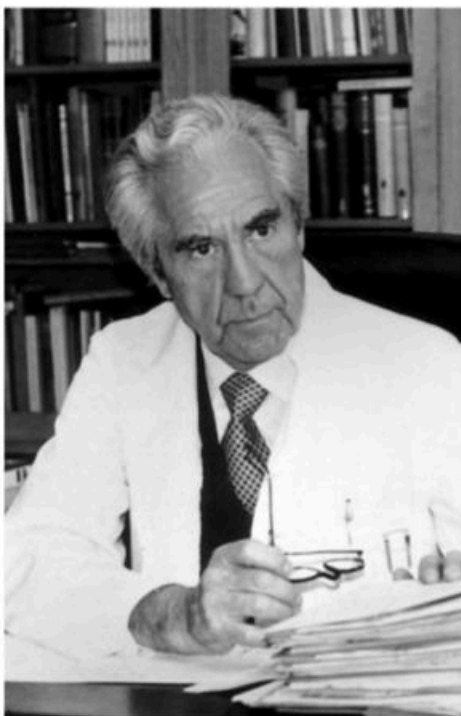
In 1954 Walton Lillehei operated on a 3 year old boy using human cross circulation who lived upto 67 years of age.



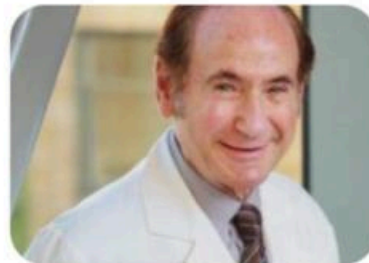
In 1954 Inge Elder (right) and Carl Hellmuth Hertz (left) used the ultrasound to examine the heart, that is echocardiography.



In 1955 John W Kirklin refined the heart lung bypass machine via a pump oxygenator.



In 1958 Ake Senning implanted the first permanent pacemaker.



In 1960 Albert Starr (top) and Dwight Harken implanted the first prosthetic heart valve.



In 1963 William Thornton Mustard did the first Mustard cardiovascular procedure for TGA.



On 3rd December 1967, Christian Barnard (top) did the first human to human heart transplant. Three days later on 6 th December Adrian Kantrowitz (bottom) transplanted the heart of a brain dead infant into another infant, which stopped functioning just after 7 hours.



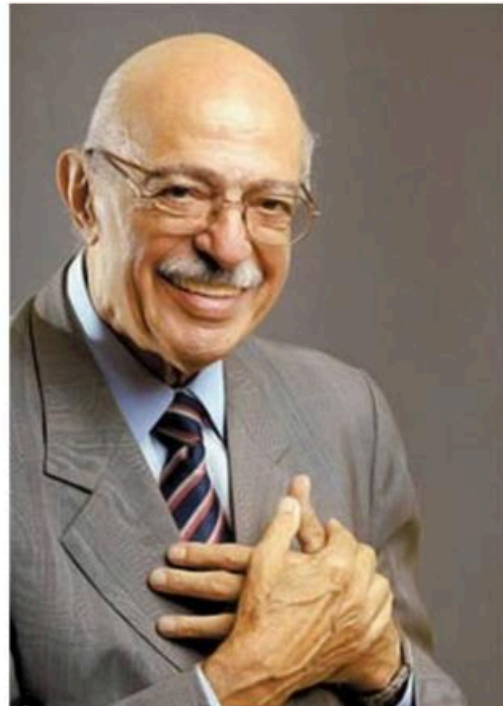
In 1966 William Rashkind introduced the balloon atrial septostomy for TGA.



In 1967 Donald N Ross performed the first pulmonary autograft or double switch procedure or Ross procedure.



In 1971 Francois Marie Fontan described a palliative surgical procedure for single ventricle kids. (Fontan surgery)



In 1976 Adib Jatene performed the first successful arterial switch operation for TGA.



In 1981 William Norwood developed a surgical procedure for HLHS (Norwood surgery)

Our Webinars

*Note: Our group members have different individual Facebook pages and Facebook groups, namely **Justice for Heart Warriors**, **Hope**, **Congenital Heart Defect Awareness Campaign**, and **Congenital heart disease India**. We are organizing webinars with renowned paediatric cardiologists and paediatric cardiac surgeons of different hospitals in India regularly. (Also, we share health/patient education videos for CHD awareness on our groups and pages.) Following is a list of webinars we have conducted so far, sometimes collectively and sometimes individually under the banner of our own page or group.*

1. Unofficial Webinar with
Dr. Benedict Raj and Dr. Srinath Reddy in December 2020
2. 1st Webinar on 13th February 2022
Topic: **CHD – Issues, Concerns and Solutions**
Speakers:
Dr. Sunil G S, Lisie Hospital, Kochi
Dr. Rajesh Sharma, Indraprasha Apollo Hospital, Delhi
Dr. S Mani Ram Krishna, Tiny Hearts, Thanjavur
Dr. Navneetha Sasikumar, Amrita Hospital, Kochi
Dr. Smita Mishra, Manipal Hospital, sector 6 Dwarka, Delhi
Dr. Mahesh Kappanayil, Amrita Hospital, Kochi
3. 2nd Webinar on 4th March 2022
Interactive session with
Dr. Brijesh P K, Amrita Hospital, Kochi
4. 3rd Webinar on 10th April 2022
Topic: **Insurance, Disability benefits and Medical fitness criteria for CHDs**
Speaker: *Dr. Smita Mishra, Manipal Hospital, Delhi*
5. 4th Webinar on 13th August 2022
Topic: **Organ Donation and Transplantation**
Speaker: *Dr. Julius Punnen, Narayana Health, Bangalore*

6. 5th Wwebinar on 30th September and 1st October 2023

Speakers:

Dr. Amitabha Chattopadhyay, Narayana Super Speciality Hospital, Howrah

Dr. Rishika Mehta, Narayana Super Speciality Hospital, Howrah

Dr. Swati Garekar, Fortis Hospital, Mumbai

Dr. Anjan Bhattacharya, Apollo Multispecialty Hospital, Kolkata

Smt. Asha Gopalakrishnan

Smt. Susan Itty Varikattu

7. 6th Webinar on 14th February 2024

Speakers:

Dr. Anita Saxena, VC, Pt. BD Sharma University of Health Sciences and Research, Rohtak

Dr. Rajesh Sharma, Marengo Asia Hospital

Dr. R Krishna Kumar, Amrita Hospital, Kochi

Dr. Smita Mishra, Manipal Hospital, Sector 6 Dwarka, Delhi

Dr. Anand Bhat, Bangalore

8. 7th Webinar on 25th May 2024

Virtual Meet and Greet

For CHD Warriors and their caregivers

9. 8th Webinar on 16th June 2024

Counselling session for caregivers

Speakers:

Ms. Sajani Nair, Kozikode

Ms. Aditi Patra, Kolkata

10. 9th Webinar on 13th August 2024

Topic: **Organ Donation and Its Importance**

Speakers:

Priyanka Borah, CEO, Zuble Foundation

Heart Recipient *Dhanshree Mujmule*

Heart Recipient *Suhana Shaikh*

Heart and Double Lung Recipient *Riza Fatima*

11. 10th Webinar on 18th December 2024

Topic: **Integrating Global Health Economics to Achieve Universal Coverage (Tackling CHD and Disabilities through Ayushman Bharat)**

Speakers:

Dr. Smita Mishra, Manipal Hospital, Sector 6, Dwarka, Delhi

Ms. Amy Verstappen, President of Global Alliance for Rheumatic and Congenital Hearts

Panel discussion:

Moderated by *Dr. Anita Saxena*, AIIMS, Delhi

Panelists: *Dr. Anjan Bhattacharya*, Apollo Multispecialty Hospital, Kolkata

Dr. Debasis Das, Narayana Superspecialty Hospital, Howrah

Dr. Mani Ram Krishna, Tiny Hearts, Thanjavur

Dr. Vikas Kohli, Director and Founder Trustee of Children Hearts Foundation

Dr. Shruti Prabhu, Narayana Health, Bangalore

Dr. Bijoy E, Joint director of State Health authority and state program manager for NHM Kerala

Mr. Alok Kumar Singh, RA, CSEP, New Delhi

Ms. Shambhavi Ravishankar, Legal and Public Health Consultant

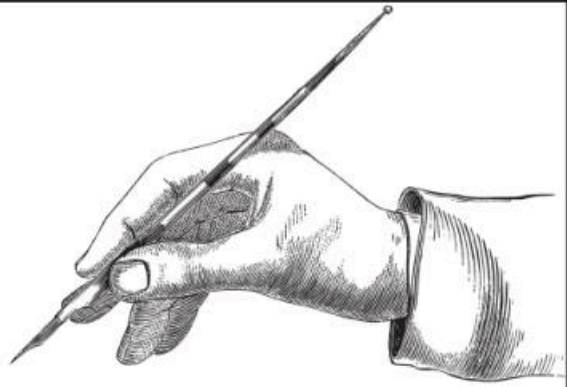
12. 11th Webinar on 25th May 2024

Virtual Meet and Greet

For CHD Warriors and their caregivers

Some people climb mountains, some get to
have heart surgery/surgeries in their
childhood.

Editorial



CHD stands for congenital heart defect. Congenital means present since or before birth. Roughly 1 in every 100 is born with CHD. In India CHD is not covered by insurance companies even CHDers are not covered for non cardiac issues.

Justice for Heart Warriors is a group of caregivers of CHDers and adult CHDers from different parts of India. We formed a WhatsApp group of heart moms (moms of CHD kids) in March 2019.

In the beginning we supported each other morally and emotionally. We discussed what can be done for the benefit of the CHD kids and adult CHDers in India. Our main concerns were

1. Insurance coverage for CHD
2. Reservation for CHDers in education and employment.

Slowly the number of members increased. And in October 2020 a bigger WhatsApp group of adult CHDers and CHD parents and a few paediatric cardiologists was formed.

Towards the end of 2020, we started a letter writing campaign. We wrote to our respective state health ministers first. After that we wrote individual letters to the PM, Government of India. They replied, but unfortunately it was not of much help for the CHD community.

Now we are connected with many experts in paediatric cardiology who support our cause.

Slowly and steadily we are trying to do our best.

We felt the necessity of a magazine on CHD for the CHD awareness of Indian people. We hope to help the CHD community of India with the valuable advice from the experts in the field of paediatric cardiology. We thought that the Indian CHD caregivers and the adult CHDers would get a proper platform to share their own experiences, which would be a great support for all of us in our journey.

We will try to bring out this magazine HRIDAY GĀTHĀ twice in a year. Since we are all from CHD community so there is a risk of editor being busy inside the hospital and thus not being able to be punctual in this case, and we hope it is understandable and acceptable.

For this inaugural issue of HRIDAY GĀTHĀ we had not fixed any theme. It has covered the CHD (congenital heart defects) in general.

Our next issue will be edited by Dr.. Suchismita Halder from Kolkata.

Let's Challenge Heart Defects together.

