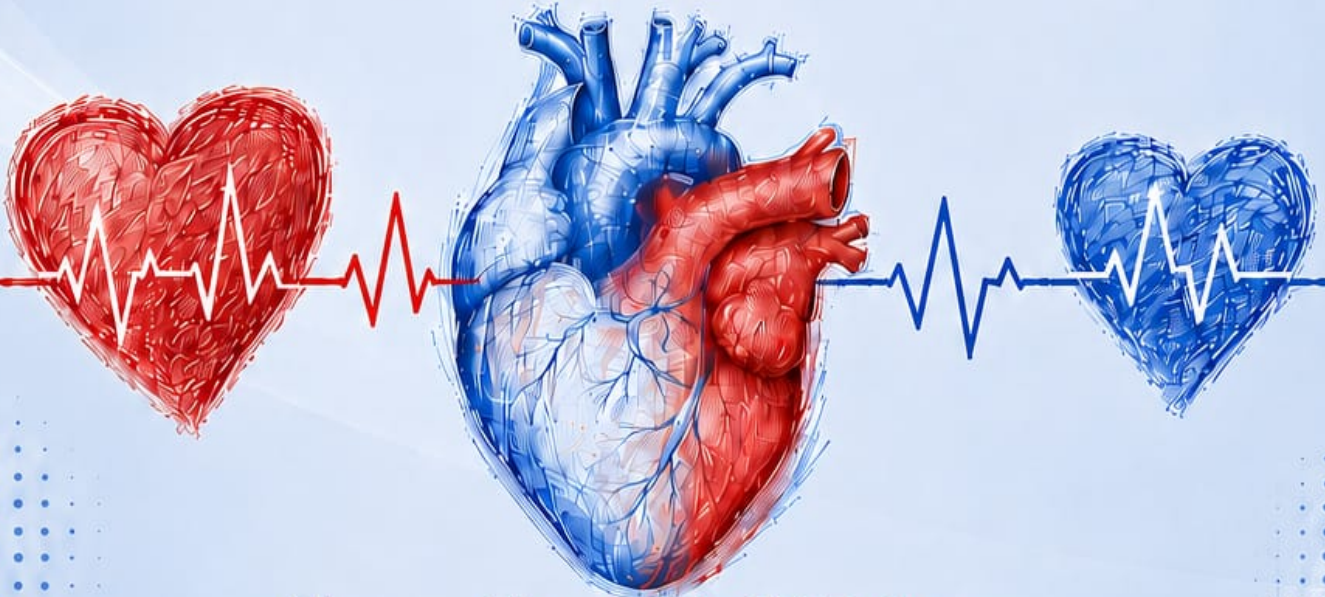




HRIDAY GĀTHĀ

♥ Stronger Hearts. **Brighter Futures.** ♥



Theme- **The Adult CHD Story**

Editor- Nikhil Shah

A Biannual Publication By

Congenital Heart Care Foundation

(Formerly Justice for Heart Warriors)

Jan-June 2026

VOLUME 2 | ISSUE 1





HRIDAY GĀTHĀ

हृदय गाथा

Stories of Heart Warriors

Volume II | Issue I

A magazine by and for the Congenital Heart Disease community
Featuring the voices of patients, parents, and medical experts

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IN LOVING
MEMORY

OF

Appu

A founding member,
torchbearer, and true
warrior of our CHD family.

Your courage inspired us,
your strength guided us,
and your legacy will live on
in every life you touched.

Forever in our hearts.



Acknowledgement

The Editorial Board of *Hriday Gatha* extends its heartfelt gratitude to everyone who contributed to making this issue possible.

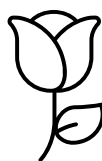
We sincerely thank the children and adults living with congenital heart disease (CHD), their parents, families, and caregivers for courageously sharing their personal journeys. Your stories of resilience, hope, and determination are the heart of this magazine and serve as an inspiration to countless others.

We are deeply grateful to the paediatric cardiologists, cardiac surgeons, physicians, nurses, researchers, rehabilitation specialists, and healthcare professionals who generously shared their expertise and valuable insights. Their unwavering commitment to improving the lives of individuals with CHD continues to inspire hope and advance patient care.

We acknowledge the authors, reviewers, photographers, artists, volunteers, and well-wishers whose time, creativity, and dedication have enriched this publication. We also thank all contributors who provided photographs and other materials and granted permission for their inclusion in this magazine.

Our sincere appreciation goes to our supporters and partner organizations whose encouragement and cooperation have helped us further the mission of promoting awareness, education, and advocacy for congenital heart disease.

Finally, we express our deepest gratitude to our readers. By reading, sharing, and supporting *Hriday Gatha*, you become an integral part of a growing community committed to improving awareness, fostering compassion, and ensuring that every individual born with congenital heart disease receives the understanding, care, and opportunities they deserve.



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**"The strongest hearts are not those that never break,
but those that keep beating through every storm."**



Preface

The Heart That Keeps Beating

There is a particular kind of exhaustion that comes not from the surgeries, not from the medicines, not even from the hospital stays, but from the constant weight of being seen as someone fragile. Someone to be careful around. Someone whose life is quietly expected to be smaller than everyone else's. For most of us living with Congenital Heart Disease, the fight was never just with our hearts. It was with a world that looked at us and saw only a patient, when all we ever wanted was to be seen as a person. Ordinary. Unremarkable. Just like everyone else.

That longing... so simple, and yet so hard to reach, is where this issue begins.

This One Is Personal

I will be honest with you. I am not a writer. I am not a lifelong advocate. I am an adult living with CHD who spent years quietly hiding that fact from almost everyone around me, colleagues, acquaintances, and the world in general. My dream was never extraordinary. I did not want to climb mountains or inspire anyone. I just wanted an ordinary life. To be treated like a healthy person. That was it. That was the whole dream.

For a long time, I carried my condition like a secret, something to be managed privately, never spoken about, certainly never leading with. It was only when I found this community that something shifted. Slowly, I stopped hiding. And somewhere along the way, I realised I could speak about my heart openly, without hesitation, without shame, in front of anyone.

That shift, from hiding to speaking, from surviving to living, is what this issue of Hriday Gatha is about. We are not the only ones who have walked this road. And this issue is for every adult with CHD who is somewhere in the middle of that journey, still figuring out what living well even means for them.

Voices In These Pages

Within these pages, you will find voices that will feel familiar, patients who have loved, struggled, built careers, asked uncomfortable questions, and refused to let CHD be the only thing that defines them. You will find parents who have fought not just for their children & health but for their place in the world.

We have not stayed in safe territory. The conversations in this issue are honest ones, the kind that usually happen in hushed tones, if they happen at all. We hope reading them feels less like a magazine and more like sitting with someone who truly gets it.

In Memoriam — Appu K. George

A Founding Member of Justice for Heart Warriors

Before you go any further, we need to stop for a moment.

A few days ago, our community lost Appu K. George — the legend who founded this community, and in doing so, gave all of us a place to belong. Appu was himself an adult living with CHD. He did not build this community from a position of comfort or distance. He built it from the inside, because he believed that people like us deserved to find each other.

Those who were with him in his final days speak of a man who did not complain, did not surrender to his pain, and never once let fear take over. There was a stillness in the way he faced what came, a kind of quiet, unshakeable dignity that, looking back, feels like everything he stood for. This magazine exists because of the community he believed in enough to build from nothing.

That is a legacy that does not need a byline.

We dedicate this issue to him, not just in grief, but in gratitude. And in the hope that the way we carry this forward is something he would have been glad to see.

Rest now, Appu. We have it from here.

Before You Begin

To everyone reading this — whether you are living with CHD, loving someone who is, or simply trying to understand what this life feels like from the inside — I hope these pages give you something real. Something that makes the road feel a little less lonely, and the future a little less uncertain. We do not have all the answers. But we have each other. And sometimes, that is

With warmth,

Nikhil Shah

Chief Editor, HG V2.1





*Born with a heart that's uniquely made,
Never by limits or labels swayed.
Every heartbeat is proof to see,
Strength begins with bravery.*

Congenital Heart Care Foundation

From lonely parents to a pan Indian organization

Dr. Jonali Choudhury (Ph.D), Guwahati, Assam

After my child's diagnosis and the first surgery, I started searching for people with CHD. I found many people from different countries but very few from India. Then I checked the members list in different CHD pages and CHD groups. Whenever I found some Indian surname, I contacted them. This way I got to know some CHD parents from India. One of them was Manjushree Chavan from Maharashtra. It was March 2019. She called me, and we talked for a long time. We both were concerned about our children's future, their health, their education, and their career. I remember we talked about including CHD as a disability on that day. Then she created a WhatsApp group— Heart to Heart with three members: Manjushree and Krutika from Maharashtra, and Jonali from Assam.



Jonali Choudhury



Manjushree Yogesh
Chavan



Krutika Salvi

Then we started asking the CHD moms we were already in contact with if they wanted to join this WhatsApp group. Gradually, this group became a large group of Indian CHD moms, supporting each other during tough times. It was such a relief and peace for us to vent to moms in a similar situation.

Then we found some fathers were also interested in joining this. So, another group was formed by Appu K. George from Kerala. It was named Special Hearts of God. Appu, who was himself a CHD warrior, included many CHD parents, adults living with CHD, a few pediatric cardiologists, and pediatric cardiac surgeons in the group. Amod Kushwaha from Uttar Pradesh included many parents who were going to AIIMS, Delhi, for their children's treatment. Dr.



Amod K. Kushwaha



Appu K George

P. Rajasekhar from AIIMS encouraged several parents to join this group.

We met online for discussions on different issues related to CHD.

We had the opportunity to interact with Dr. Benedict Raj and Dr. Srinath Reddy during a virtual meeting. Appu K. George and Sajani Nair from Kerala, and Jonali Choudhury

from Assam joined that meeting. Dr. Benedict sir advised us to create a website and enter all information related to CHD treatment there, like hospital names, doctors' names, etc. Then, during the COVID-19 pandemic, Sajani Nair suggested that we write to the Ministry of Health outlining our concerns and recommendations. So, we first sent letters (via postal services) to the Health Ministers of the states and, after some days, to the PMO. Unfortunately, we got no proper responses.

We realized that we should have a legal identity — a registered organization for us. We asked in the groups if they were interested in the registration, and some of us came forward.

Meanwhile, during the CHD Awareness Week, 2022, we organized our first formal webinar with multiple doctors. It was a very long program, and it was so empowering and motivating. We got to know Dr. Smita Mishra madam and Dr. Rajesh Sharma sir who were already trying to get insurance coverage for CHD and to get CHD included in the disability list.

After that meeting, Dr. Smita Mishra Madam was with us continuously, and she is a big support for us.

In the meantime, Suchismita Halder from West Bengal joined our group, and since then she has undoubtedly become one of the most energetic and active members of our group.

Somehow the process of registration took too long to happen, and we had some bitter and frustrating experiences too.

Till now we have organized 15 webinars and published two issues of our own magazine, **HRIDAY GATHA**. In fact, I am writing this article for the third issue of Hriday Gatha!

After a long period of trying, finally on 25th May 2026, we registered our group in Kolkata. Now our formal name is Congenital Heart Care Foundation. This is a journey from lonely, depressed CHD parents to a united, strong, determined pan Indian organization. We have lots of plans to execute soon.

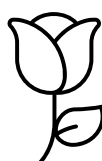
We hope the **Congenital Heart Care Foundation** will drive meaningful and lasting positive change for the congenital heart disease community in India.



Sajani Nair T. R.



Suchismita Halder





At the lawyer's office



At our registered office

"Congenital heart disease is a diagnosis, not a definition."



"Scars are not reminders of weakness. They are proof that you survived and kept moving forward."

Expert Speaks: An Interview with Dr. Anita Saxena

Interviewer: Pritisudha Sharma, Kolkata



Dr. Anita Saxena

About Dr. Anita Saxena

Dr. Anita Saxena is one of India's most distinguished paediatric cardiologists, academic leaders, researchers, and mentors. With over four decades of experience in clinical care, medical education, research, and healthcare administration, she has played a transformative role in advancing paediatric and congenital heart care in India and beyond.

A graduate of AIIMS, New Delhi with MBBS, MD (Medicine), and DM (Cardiology), Dr. Saxena spent more than 36 years at AIIMS, New Delhi, where she served as Dean (Academics), Chief of the Cardiothoracic Centre, and Head of the Department of Cardiology. Following her retirement from AIIMS in 2021, she served as Vice Chancellor of Pt. B. D. Sharma University of Health Sciences, Rohtak.

Dr. Saxena pioneered fetal cardiology services in India and has been instrumental in developing national guidelines for the management of paediatric heart diseases. She has authored over 370 scientific publications, mentored more than 40 postgraduate and doctoral students, and delivered numerous invited lectures worldwide. Her outstanding research contributions earned her a place in Elsevier–Stanford University's list of the World's Top 2% Scientists in 2023, 2024, and 2025.

Currently, she serves as Executive Director of Paediatric Cardiology and Head of Non-Invasive Cardiology at Fortis Escorts Heart Institute, New Delhi, and as President of AIIMS Bhubaneswar. A recipient of Lifetime Achievement Awards from both the Paediatric Cardiac Society of India and the Cardiological Society of India, Dr. Saxena continues to inspire excellence in patient care, education, and research.

Edited Transcript of Telephonic Interview with Dr. Anita Saxena Interviewer is Pritisudha Sharma from Kolkata.

1. Managing Emergencies & Follow-up Care in Tier 2/Tier 3 Cities

Pritisudha Sharma: Unlike metro cities we do not have excellent medical setups all over the country, like in Tier 2 and Tier 3 cities, whom should CHD patients (whether operated or unoperated) contact in an emergency or for routine care if their primary cardiac team is in another city or state?

Dr. Anita Saxena: As far as emergencies are concerned, you must go to your nearest hospital. You simply cannot wait to travel to another city or for your specific doctor to become available. Emergencies generally fall into three or four categories: a sudden drop in blood pressure, worsening

heart failure, sudden severe breathlessness, or a sudden, rapid change in heartbeat. These situations can be managed in the emergency department of any good hospital.

You just need to carry your complete medical history and surgical records to show the emergency team. Emergency treatment can be done at any good hospital because time is of the essence.

Pritisudha Sharma: How will a patient know they are facing an emergency? What specific symptoms can we notice ourselves?

Dr. Anita Saxena: If a patient has been going for regular checkups, their doctor usually educates them on the warning signs. However, patients who skip follow-ups won't know this. In our country, many patients undergo surgery but are not educated properly regarding follow-up. They assume that post-surgery is permanently fixed, so they stop routine follow-ups.

It is crucial to understand that except for some simple childhood surgeries, lifelong follow-up is necessary—even if the patient has no symptoms. Regular follow-ups often prevent emergencies from happening in the first place.

Regarding emergency symptoms, you are looking for a sudden exacerbation of a routine symptom. Mild breathlessness or fatigue might be normal for a patient, but if they suddenly become severely breathless while just sitting or doing minimal activity, that is an emergency.

Warning Signs of an Emergency

- Sudden Increase in Breathlessness: Especially if the patient was previously stable.
- Sudden Rapid Heartbeat (Arrhythmia): A sudden, unusually fast pounding of the heart that impedes normal heart function and can lead to heart failure if untreated.
- Fainting or Dizziness (Syncope): Collapsing, blacking out, or feeling dizzy should never be ignored, as it can be caused by a severely slow or fast heartbeat.
- Continuous Chest Pain: New, persistent chest pain that does not subside.

If you experience any of these, you must immediately visit the best available hospital nearby.

Additionally, symptoms like gradual body swelling or a gradual decrease in urine output shouldn't be ignored, as they can slowly turn into emergencies if left untreated.

Noticeable Symptoms for Toddlers & Young Children

Pritisudha Sharma: While an adult CHD patient can verbalize their discomfort, what symptoms should parents look out for in young children (1 to 4 years old) who cannot explain their problems?

Dr. Anita Saxena: Parents must closely observe the child's behavior and physical signs, as the child cannot complain verbally.

Key Symptoms in Toddlers & Infants:

- Refusal to Feed: The very first symptom, especially in infants under one year, is refusing to drink milk or eat food.
- Decreased Urine Output: A noticeable drop in how much the child is urinating.
- Rapid Breathing: Instead of a normal 30-35 breaths per minute, the child might be breathing heavily at 50-60 breaths per minute.
- Extremely Fast Heartbeat: If you place your hand on their chest and the heart is beating so fast that you cannot even count it.
- Repeated episodes of vomiting

Exercise and Physical Activity Guidelines

Pritisudha Sharma: Generally speaking, what types of exercises and physical activities are safe for CHD patients?

Dr. Anita Saxena: Exercise plays a highly important role for every congenital heart patient, even post-surgery. It improves the heart's conditioning and endurance, and establishing a routine profoundly benefits the patient's mental health and comfort.

Exercise Guidelines for CHD Patients:

- **Stay Within Comfort Limits:** Patients should never push themselves beyond what they can comfortably tolerate. This is especially true for complex conditions like Fontan circulation, where the underlying heart disease remains despite surgery. Competitive sports are generally discouraged.
- **Focus on Isotonic Exercises:** Choose exercises that involve continuous muscle movement, such as cycling, running, swimming or walking.
- **Avoid Isometric Exercises:** Exercises without body movement, classically heavy weightlifting (where you just hold a weight for 30-40 seconds), should be avoided. Young people going to the gym must be mindful of this.
- **Leg Exercises for Fontan Patients:** Lower limb exercises (cycling, treadmill, yoga) are highly beneficial for Fontan patients because muscle movement helps pump blood upward against gravity.
- **Fully Corrected Conditions:** Patients with fully closed VSDs or ASDs with no residual problems are considered completely normal and have no exercise restrictions whatsoever.

2. Precautions Before Non-Cardiac or Dental Procedures

Pritisudha Sharma: What should I know before undergoing a non-cardiac surgery, medical, or dental procedure?

Dr. Anita Saxena: The most important factor is whether you have any residual problems or implants from your heart surgery. If you have an artificial conduit (tube) or a metallic valve implanted, you are at risk of infection, more so within the first 6 months post-surgery.

Dental Procedures: You must inform your dentist so they can administer an antibiotic one hour prior to the procedure under local anesthesia.

Major Non-Cardiac Surgeries: For surgeries requiring general anesthesia (like gallbladder or kidney stone removal), prior cardiology clearance is mandatory. The anesthesiologist will need a written note from your cardiologist confirming it is safe to operate, outlining specific surgical precautions based on your condition, and prescribing any necessary antibiotics.

3. Glenn Shunt vs. Fontan Surgery Complications

Pritisudha Sharma: Can we avoid Fontan surgery and stay only with Glenn? What are the complications in that case?

Dr. Anita Saxena: The Glenn procedure is essentially a "half-Fontan." In Glenn, we direct the blue (deoxygenated) blood from the upper body directly into the lungs, but the lower body's blue blood still mixes with the red blood in the heart. Therefore, oxygen levels are never fully normalized after just a Glenn.

Glenn is the first stage of surgery to be followed by a Fontan, not a final operation. If a child is suitable for a Fontan after a Glenn, they absolutely must get it.

Risks of Stopping at Glenn:

Lower Oxygen Levels: The body continues to experience mild oxygen deprivation (cyanosis).

Risk of Brain Infection: Because blue and red blood continue to mix, any minor bodily infection (like a wound or a boil) can easily travel through the bloodstream and infect the brain.

Every Glenn patient should proceed to a Fontan unless their cardiologist and surgeon determine they are medically unfit (for instance, if there has been a 10–15-year gap after the Glenn or any other reason where Fontan will be very high risk). A Fontan significantly normalizes oxygen levels and eliminates the mixing of blood.

4. Monitoring Systemic Right Ventricle (Heart Failure & Rhythm)

Pritisudha Sharma: What are the key things you look for when monitoring adults with a systemic right ventricle for heart failure or rhythm problems?

Dr. Anita Saxena: These patients must have regular checkups, including echocardiograms, ECGs, and sometimes 24-hour Holter monitoring. Since a systemic right ventricle is likely to struggle over time, early detection is key.

The core concept is prevention. If we detect early signs of ventricular decline or minor arrhythmia, we can introduce medications that preserve heart function and control rhythm, extending the ventricle's lifespan to 40-50 years. Waiting until severe symptoms appear is dangerous and can result in irreversible heart damage.

5. Pacemakers and ICD Implantation Indications

Pritisudha Sharma: What factors determine the need for a pacemaker or ICD (Implantable Cardioverter-Defibrillator) in adults with CHD, and how do the indications differ from the non-congenital population?

Dr. Anita Saxena: The primary indications are the same as the general population:

Pacemakers: Used for heart block or dangerously slow heartbeats. In CHD, we are slightly more liberal (e.g., placing a pacemaker at a heart rate of 60 rather than waiting until 55) because these hearts require a slightly higher baseline rate.

ICDs: Used to prevent sudden cardiac death caused by dangerous arrhythmias, specifically Ventricular Tachycardia (VT), or in cases of severe heart weakness and fainting (syncope). This is common in patients with old surgeries (like Tetralogy of Fallot) whose ventricles have dilated over time.

The Major Difference in CHD:

Before implanting an ICD in a congenital heart patient, we always look for a correctable structural cause. For example, if severe pulmonary regurgitation is causing the right ventricle to dilate and trigger arrhythmias, fixing the valve can heal the ventricle and eliminate the need for an ICD.

6. Long-Term Risks of Fontan Circulation

Pritisudha Sharma: Our next question is: What are the long-term risks of Fontan circulation and heart failure, which can lead to a transplant?

Dr. Anita Saxena: Fontan circulation has a specific duration. It is not a physiological circulation; it is an unphysiological one because it relies on only one ventricle, whereas normal circulations have two. We perform the Fontan procedure, but we know that over a period of many years, the circulation will eventually fail.

- **Follow-up Care:** We must continuously monitor the patient to ensure the Fontan circulation isn't causing diseases in the liver, kidneys, or the heart itself.
- **Medical Interventions:** If we find an issue that can be corrected, we address it through medication or surgery.
- **Ultimate Reality:** Even the best Fontan circulation will start to fail after 30 to 35 years. At that stage, when the heart function deteriorates and we have exhausted all medical and surgical options, cardiac transplantation becomes the only viable treatment. Not everyone, but a significant number of patients, will eventually require a heart transplant after 35 to 40 years. Newer advances may change this situation in future

7. Managing Pulmonary Hypertension in Eisenmenger Syndrome

Pritisudha Sharma: What are the main challenges in managing pulmonary hypertension in Eisenmenger syndrome for adult congenital patients?

Dr. Anita Saxena: In Eisenmenger syndrome, pulmonary hypertension is a definite occurrence. We manage it using the same medications typically prescribed for pulmonary arterial hypertension (PAH). There are about three or four such medicines available in the market.

When to Treat: Medication should only be started when the patient becomes symptomatic. If a patient is living comfortably with oxygen saturation levels above 85-90% without significant breathlessness, medication may not be necessary.

Symptom Management: These medicines will not cure inherent pulmonary hypertension, but they will improve the patient's symptoms and oxygen levels.

Oxygen Therapy: For many patients, we highly recommend home oxygen therapy. Using oxygen continuously for 6 to 7 hours at night while sleeping can slightly improve pulmonary pressure and overall oxygen levels, helping the patient feel much better.

8. Pregnancy and Family Planning for Female CHD Patients

Pritisudha Sharma: What should they know about pregnancy and family planning? Many people also ask if a patient with Congenital Heart Disease (CHD) gets operated on and later becomes pregnant, can the CHD be passed on to the baby?

Dr. Anita Saxena: There are two parts to this question. First, can they get pregnant?

Pregnancy Feasibility (Risk Categories):

Low Risk (Category 1): Patients with a closed Atrial Septal Defect (ASD), closed Ventricular Septal Defect (VSD), or a fully corrected Tetralogy of Fallot with no residual defects can safely pursue pregnancy.

High Risk (Category 4): Pregnancy is strictly prohibited and highly dangerous for patients with Eisenmenger syndrome, Fontan circulation with one or more complications, or poor ventricular function. For complicated Fontan patients, pregnancy often leads to spontaneous abortions where the fetus does not survive the first few months. We advise these patients that marriage is perfectly fine, but pregnancy should be avoided.

Passing CHD to the Child:

- **Risk Level:** Yes, it can be passed on, but the risk remains very low. The risk in the general population is about 0.8% to 1%, whereas for mothers or fathers with CHD patients, it is roughly 2%.
- **Fetal Echocardiography:** We strongly advise all mothers with a history of CHD to get a fetal echocardiogram at around 18 to 20 weeks. If a severe, incurable anomaly (like a single ventricle) is detected, the parents have the choice to terminate.
- **Delivery Planning:** Even for minor anomalies, knowing in advance allows parents to plan the delivery at a specialized hospital fully equipped with pediatric cardiac care facilities.

9. Impact on Career Choices, Travel, and Daily Life

Pritisudha Sharma: How might my condition affect my career choices, travel, and daily life in different climates?

Dr. Anita Saxena: This entirely depends on the specific heart problem.

Simple Heart Conditions: Patients with corrected ASD or VSD have absolutely zero restrictions regarding their career, exercise, climate, or air travel.

Complex Conditions (Fontan / Eisenmenger):

Career: Choices are somewhat limited. Patients should opt for desk jobs (executive, corporate, accounts) that do not require much physical exertion. They must avoid professions where they are responsible for the lives of others, such as commercial drivers or pilots.

Travel: Domestic flights (3-4 hours) are generally safe. However, air travel naturally drops oxygen saturation by 2-3%. If a patient's baseline saturation is already around 85-88%, they must be cautious and may require supplemental oxygen, especially on long-haul international flights (10-12 hours)."

10. Mental Health, Anxiety, and Stress Management

Pritisudha Sharma: Many adult CHD patients experience anxiety, stress, and depression because they have spent so much time in hospitals. Hearing stories of recurrent hospitalizations builds up a lot of pressure. What is your advice for this?

Dr. Anita Saxena: This is a very natural response to chronic stress, and it applies to any long-term illness, not just heart disease. Because it is a chronic issue, it frequently troubles the patient.

Routine: Maintain a normal daily routine. Keep studying or pursuing your profession.

Mindfulness: I specifically advise Fontan patients to dedicate 45 to 60 minutes daily to yoga or meditation. You don't necessarily need a specific instructor or location; there are plenty of guided sessions available on YouTube that you can practice at home in front of your TV.

Counseling: The goal is to incorporate relaxation into your daily life to find mental peace. However, for patients and parents experiencing severe stress, we highly recommend arranging specialized counseling sessions.

Heart Failure to Heart Transplantation: From Failing Pump to a New Heart

By **Ashish Gaur** | Lead – Program Expansion, Heart Transplantation, Sir HN Reliance Foundation Hospital, Mumbai



Ashish Gaur

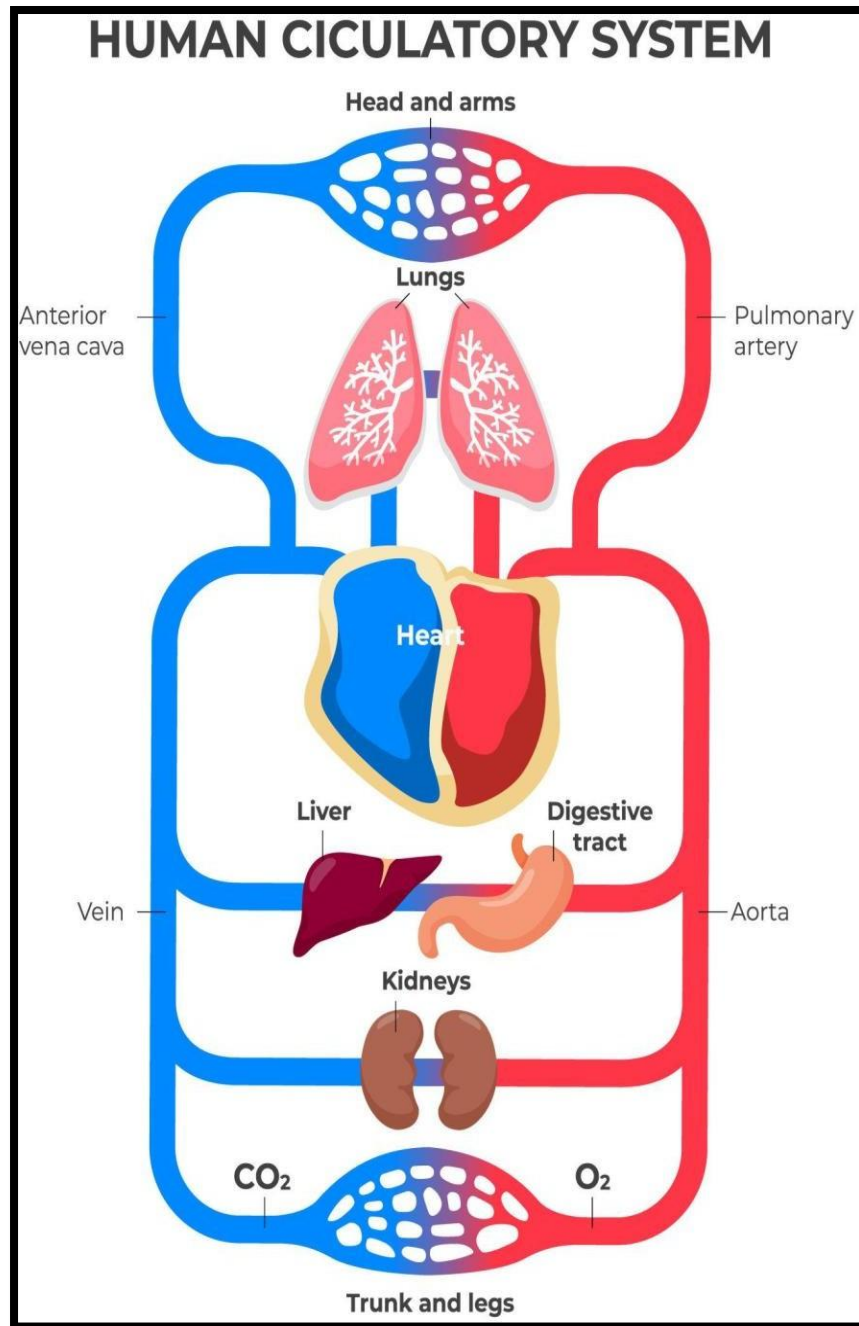
About Mr. Ashish Gaur

Mr. Ashish Gaur is a distinguished healthcare professional with over 18 years of experience in cardiothoracic surgery, advanced heart failure management, mechanical circulatory support, and heart transplantation. He serves as Lead – Program Expansion, Heart Transplantation & Advanced Cardiothoracic Surgery, and Senior Cardiovascular Surgical Associate at Sir H. N. Reliance Foundation Hospital, Mumbai. His expertise spans adult cardiac surgery, ECMO, ventricular assist device (VAD/LVAD) programmes, transplant coordination, and advanced heart failure services. A graduate of BITS Pilani, with advanced qualifications in healthcare management and strategy from Welingkar Institute and IIM Kozhikode, he combines clinical excellence with strategic leadership. Mr. Gaur is also a prominent advocate for Physician Associate education, serving in key leadership roles within national and international professional organizations. His contributions continue to advance heart transplantation and cardiothoracic sciences across India.

Heart failure represents the final common pathway of numerous cardiovascular diseases and remains one of the leading causes of hospitalisation, disability, and mortality worldwide. Despite remarkable advances in pharmacotherapy, device therapy, and surgical interventions, a substantial proportion of patients progress to advanced or end-stage heart failure — a stage at which conventional therapies become insufficient.

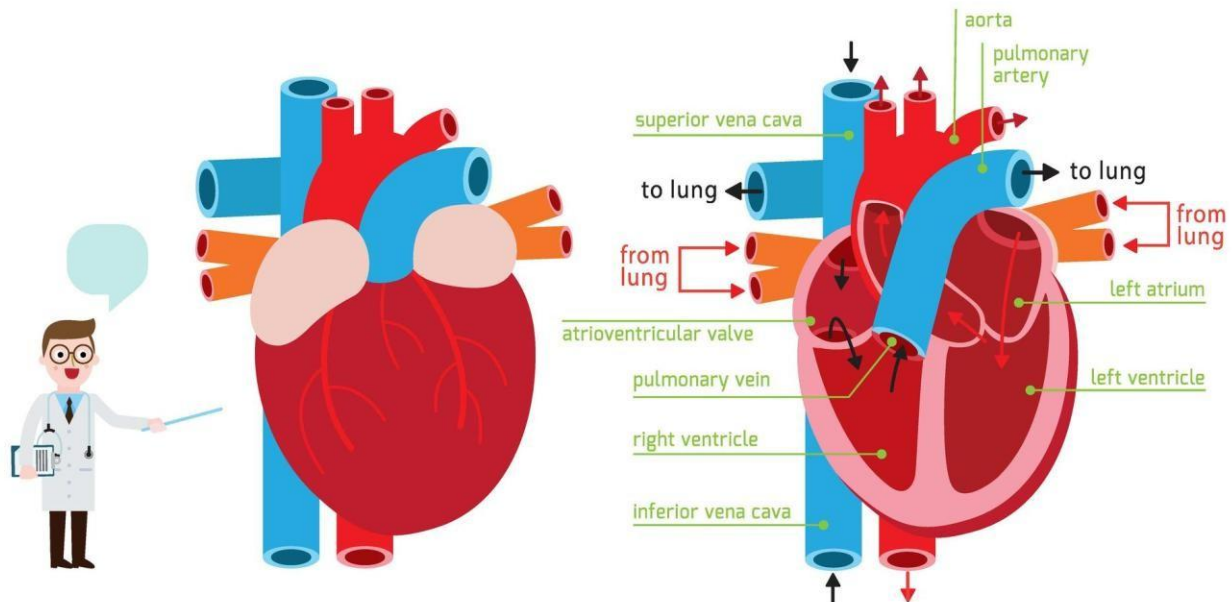
Over the past two decades, heart failure management has undergone a paradigm shift. Modern guideline-directed medical therapy (GDMT) can substantially improve survival, reverse ventricular remodelling, and reduce hospitalisations. Nevertheless, for selected patients with refractory advanced heart failure, heart transplantation remains the gold-standard treatment.

This article reviews the pathophysiology, diagnosis, contemporary treatment of heart failure, and

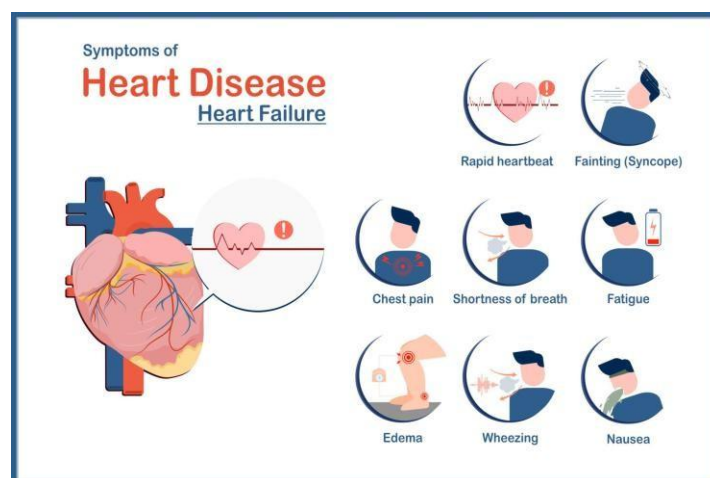


the scientific principles governing heart transplantation.

Human circulatory system.

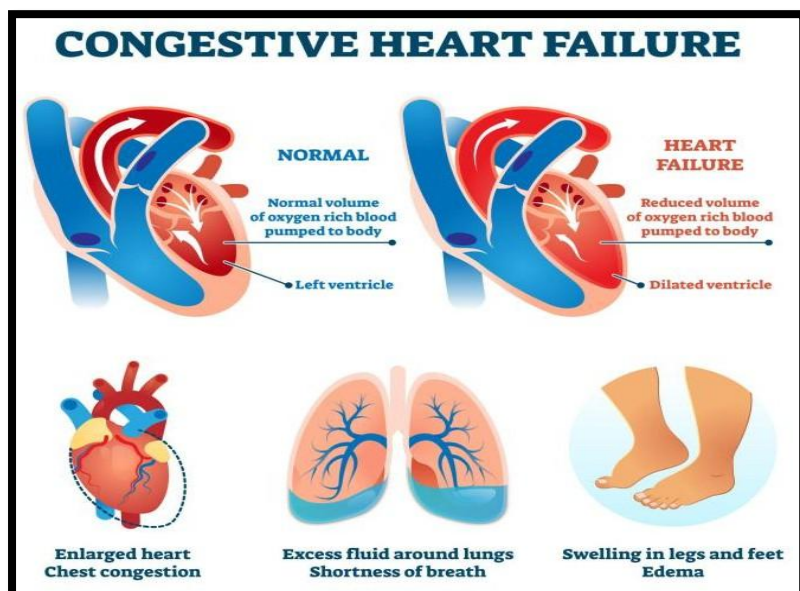


Heart failure is a clinical syndrome resulting from structural or functional abnormalities of the heart that impair its ability to fill with or eject blood adequately. The condition is characterised by breathlessness, fatigue, and reduced exercise tolerance, together with fluid retention, recurrent hospitalisations, and progressive end-organ dysfunction. Common causes include coronary artery disease, myocardial infarction, dilated cardiomyopathy, valvular heart disease, and congenital heart disease.



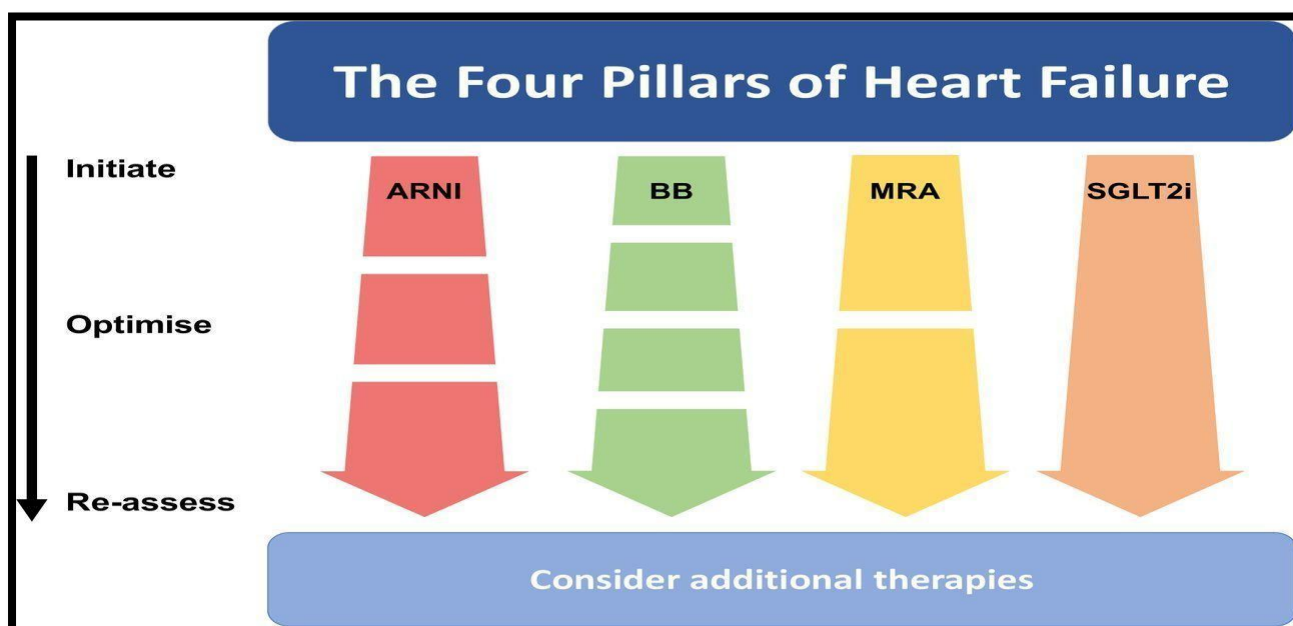
Pathophysiology and Classification

The failing heart initially activates compensatory mechanisms — neurohormonal activation, sympathetic stimulation, and renin-angiotensin-aldosterone system (RAAS) activation — that become maladaptive over time, causing ventricular remodelling characterised by chamber dilatation, myocyte hypertrophy, and interstitial fibrosis. Current guidelines classify heart failure by left ventricular ejection fraction: HFrEF ($\leq 40\%$), HFmrEF (41–49%), and HFpEF ($\geq 50\%$). The 2023 ESC update strengthened SGLT2 inhibitor recommendations across all categories.



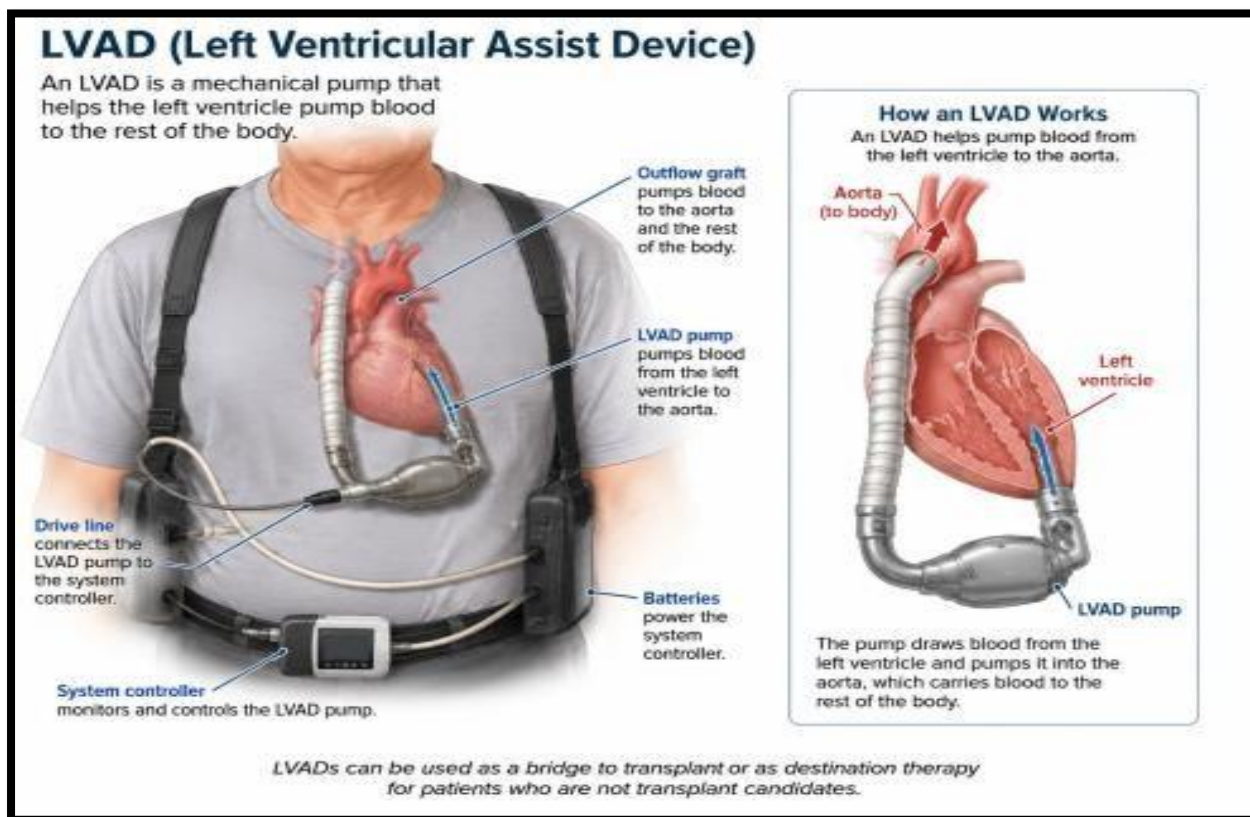
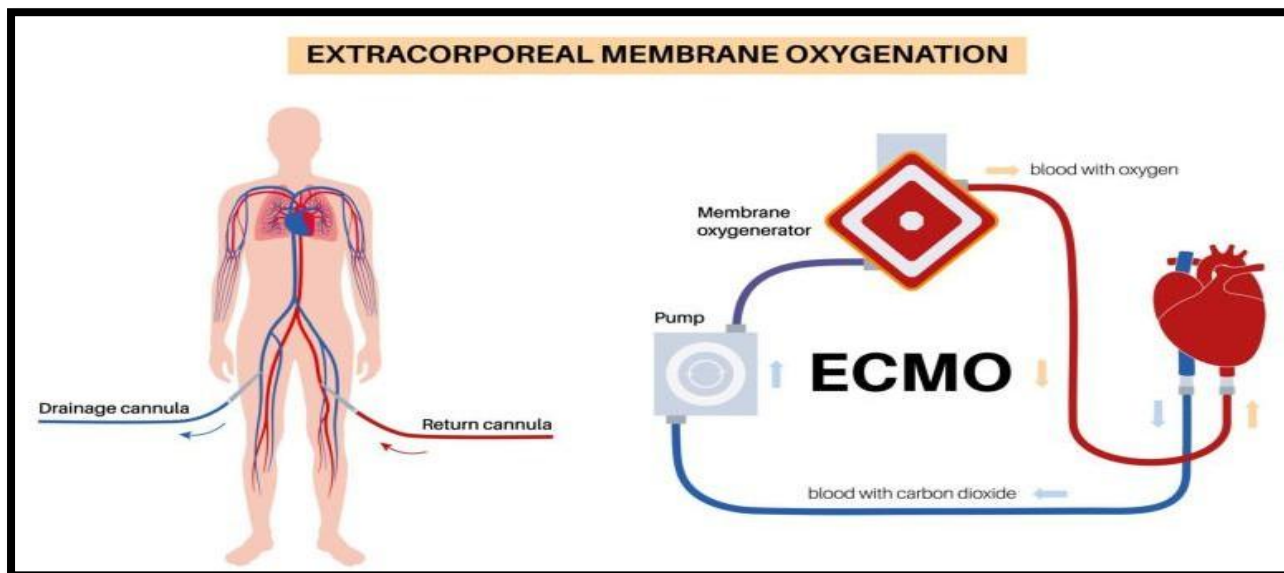
Contemporary Medical Therapy

Modern HFrEF therapy revolves around four pillars: Angiotensin Receptor-Neprilysin Inhibitors (ARNI/Sacubitril-Valsartan), Beta-Blockers (carvedilol, metoprolol succinate, bisoprolol), Mineralocorticoid Receptor Antagonists (spironolactone, eplerenone), and SGLT2 Inhibitors (dapagliflozin, empagliflozin). Diuretics remain essential for symptomatic relief. Vericiguat (Verquvo), an oral soluble guanylate cyclase stimulator, benefits high-risk patients with recent worsening heart failure.



Advanced Heart Failure and Mechanical Circulatory Support

Despite optimal therapy, some patients continue to deteriorate. Before transplantation, some require mechanical support: Intra-Aortic Balloon Pumps for temporary circulatory assistance, ECMO for short-term cardiac and respiratory support, and Left Ventricular Assist Devices (LVADs), which can serve as a bridge to transplant, bridge to decision, or destination therapy



Heart Transplantation

Heart transplantation remains the definitive therapy for carefully selected patients with end-stage heart failure, offering restoration of normal haemodynamic, excellent functional recovery, and

markedly improved survival. Contemporary one-year survival approaches 90% at experienced centres. Contraindications include fixed pulmonary hypertension, active infection, active malignancy, severe irreversible renal or liver disease, severe frailty, and inability to adhere to lifelong follow-up.

Life After Transplantation

Successful transplantation marks the beginning rather than the end of treatment. Recipients require lifelong immunosuppression — typically tacrolimus, mycophenolate mofetil, and corticosteroids — along with infection prevention medicines. Despite the challenges, most recipients experience dramatic improvements in quality of life, returning to employment, travel, sports, and family life for years and often decades following transplantation.

Heart transplantation remains one of the most remarkable achievements in modern healthcare — transforming end-stage heart failure from a terminal condition into the possibility of a new life

Why Does Someone Need a Heart Transplant?

A heart transplant is considered when the heart has become so weak that it can no longer pump enough blood to support the body's needs, despite the best available treatments including heart failure medications, pacemakers, defibrillators, bypass surgery, valve surgery, and temporary mechanical support devices.

Finding a Suitable Donor Heart

Doctors carefully match blood group, body size, medical compatibility (the donor heart must be healthy and free from major structural abnormalities), and immunological compatibility (blood tests help determine whether the recipient has antibodies that may attack the donor heart).

Organ Procurement: How the Donor Heart Is Retrieved

When a suitable donor becomes available, a specialised transplant retrieval team travels to the donor hospital. A special cold preservation solution stops the heartbeat safely, reduces energy consumption, and protects heart muscle cells. The period during which the heart is outside the body is called the ischaemic time. The shorter this period, the better the chances of excellent heart function after transplantation.

The Heart Transplant Operation

The surgeon divides the breastbone through a median sternotomy and connects the patient to a cardiopulmonary bypass machine. Most of the patient's failing heart is removed, and the donor heart is carefully sewn into position with connections to the left atrium, right atrium or vena cava, pulmonary artery, and aorta. Blood flow is restored and the heart frequently begins beating spontaneously. The operation typically lasts 4–8 hours.

Risks, Recovery and Rejection

Major risks include bleeding, primary graft dysfunction, stroke, kidney failure, and death — though modern survival rates exceed 90% at one year in experienced transplant programmes. The immune

system cannot naturally distinguish a life-saving donor heart from a harmful invader. Without treatment, immune cells attack the transplanted heart in a process called rejection. Modern immunosuppressive medications — tacrolimus, mycophenolate mofetil, and prednisolone — have dramatically reduced rejection rates, but lifelong vigilance remains essential.

Life at Home After Transplant

The first year requires particular attention. Medications must be taken at exactly the prescribed times — never stopped without consulting the transplant team. To prevent infection, patients should wash hands frequently, avoid crowded places initially, and avoid contact with sick individuals. A healthy diet, regular exercise, and strict follow-up appointments are crucial.

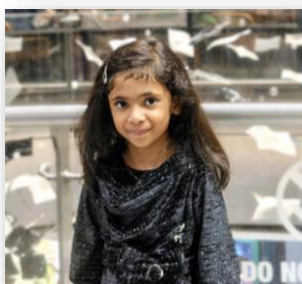
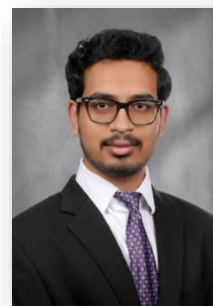
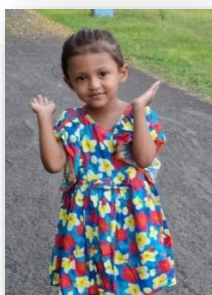
- Contact the transplant team immediately for: fever, breathlessness, sudden weight gain, swelling, persistent cough, palpitations, extreme fatigue, or reduced exercise tolerance.

A heart transplant is not simply an operation — it is a lifelong partnership between the patient, family, transplant team, and donor family.

Many transplant recipients successfully live 10, 15, 20, or even more years after transplantation. For patients facing end-stage heart failure, heart transplantation offers a genuine opportunity for renewed life, restored independence, and hope for the future.

"Early diagnosis, timely treatment, and lifelong care make all the difference."

OUR CHD WARRIORS



IN FRAMES

Rudranshi, Adhiroha, Nishat, Sidharth, Shriya, Bhavani, Ketaki,
Ribrib, Nikhil, Krishna, Raj

CREATIVE CORNER



-ADHIROHA CHAVAN (7y)



-RUDRANSHI BHOWMICK (3y)

Appu K. George (1987 - 2026)





Appu K George with Dr. R Krishna Kumar

I have had the privilege of looking after Appu K George. Appu had an extremely complex, congenital heart condition and was significantly challenged right from his early childhood. His condition imposed several limitations that he overcame through his incredible determination and indomitable spirit. He underwent too very difficult operations. The second operation, in particular, was extremely challenging, both for the caregivers as well as for himself. Following the second operation, Appu lived a reasonably productive life. He overcame several physical and psychosocial setbacks that included difficulties in finding a suitable employment and rejection at workplace.

Despite all what he went through, he worked tirelessly to help others who were affected with congenital heart disease. He was a true warrior for the cause of improving lives of patients with CHD. When he was finally diagnosed to have a leukaemia, it was a completely unexpected development that would have normally devastated anyone. However, he accepted this most unfortunate development with amazing maturity and equanimity. The messages that poured in from all over the world clearly showed how much he was loved and respected.

Appu and I shared an amazing friendship, and I have learnt so much by simply being one of his caregivers. I know that his tragic loss is the source of enormous grief to his very loving and caring family and I sincerely pray for them to have the strength and courage to overcome this enormous loss. I know that the congenital heart disease community across the world will miss him greatly. His life should be an example, and a source of inspiration for others to overcome their challenges.

Dr. R Krishna Kumar

Clinical Professor and Head, Pediatric Cardiology, Amrita Institute of Medical Sciences and Research Centre, Cochin, 682041, Kerala, India; Phone +91-484 2853570
kumar_rk@yahoo.com

Tribute to our beloved Appu K. George

Appu was a grounded individual who took his heart condition seriously; a key part of his life involved seeking out the latest information from both within the country and abroad.

Through activities such as maintaining a healthy lifestyle, working for a living, and staying active across changing seasons, he sought to demonstrate that he was not defined by his illness—an example that inspires every fighter battling heart disease. We will continue to remember Appu for his many endeavours.

-Mohiuddin Qazi

I knew Appu through the Adult CHD group from January 2026. During my Fontan journey, he guided and encouraged me with kindness and even helped us seek another medical opinion. His selfless support to me and countless CHD warriors will never be forgotten. Thank you, Appu, for inspiring us all. Rest in peace. 💙

-Bhavani Sekar

His entry into my life was through a phone call...once the conversation started it went on for hours ..cause the topic of discussion was CHD and a hundred unresolved hidden issues, waiting to be addressed. We were together in making the logo, website for Justice for heart warriors. We launched webinars...we connected with the heart warriors from within and outside India. We met in person at the Webinar conducted at Amrita hospital. We did have differences as Appu was not in favour of registration and functioning as an organisation. He was in for advocacy, and I was in for more aggressive involvements. But either way we both wanted the same thing. Justice for heart warriors. He may have left for a better place. But we shall see his dream bear fruits and our heart warriors get the stage they rightly deserve.

-Sajani Nair

I first met Appu Chetta through our CHD community, and he quickly became like an elder brother to me. He was always positive, caring, and ready to support others despite his own challenges. He regularly checked on my health and encouraged me to speak openly about CHD. He will always be remembered as a true CHD warrior and a wonderful human being. Rest in peace, Appu Chetta.

– Amritha Ashok
Fellow CHD Warrior and Friend

Appu was my guiding star in the world of CHD advocacy. Before every new initiative, he was the first person I would call. We would spend hours on the phone discussing what needed to be done, dreaming of a better future for our CHD community, and finding ways to support more families. Before every hospitalization of my son, I would speak to Appu. Somehow, no matter how difficult the situation felt, talking to him always brought reassurance, strength, and hope. He had a remarkable way of making people feel less alone.

Appu believed every CHD warrior was his brother or sister. Even during his final battle, he chose not to share too much about his own struggles because he did not want others to feel discouraged. That was the kind of person he was—selfless, compassionate, and endlessly positive.

Thank you, Appu, for your friendship, guidance, and unwavering faith in all of us. You will always remain one of the brightest lights guiding our journey

- Suchismita Halder

There are never enough words to describe Appu. He truly was an angel sent by God.

Living with congenital heart disease is incredibly difficult, yet Appu chose to dedicate his life to helping others. While managing his own challenges, he became a source of hope, support, and motivation for countless children and families in the CHD community.

Appu will always live on in our memories and in the hearts of everyone he helped. His legacy will continue to inspire us every day. We miss him dearly and pray that his onward journey is peaceful.

-Ketaki Raj

Appu's life was a testament to resilience, strength, and unwavering determination. Living with a congenital heart defect, Appu transformed personal struggle into purpose, becoming a powerful voice for countless children and families navigating similar challenges. Through advocacy, awareness efforts, and compassionate engagement, Appu worked relentlessly to ensure that children with CHD receive the care, recognition, and opportunities they deserve.

Beyond advocacy, Appu was a source of inspiration—someone who faced adversity with grace and courage. His journey touched many lives, offering hope to families and strength to young warriors fighting their own battles. He believed deeply in inclusion, equity in healthcare, and the fundamental right of every child to live a full and meaningful life.

Appu will be remembered not only for his advocacy work but also for his kindness, empathy, and indomitable spirit. His legacy will continue to inspire efforts toward better healthcare systems, increased awareness of congenital heart conditions, and a more compassionate society.

Appu K George leaves behind a community forever changed by his courage and commitment. Though gone too soon, his voice will echo in every step forward taken for CHD awareness and children's rights.

May his soul rest in peace, and may his legacy continue to guide and inspire us all.

-Amod Kumar

I had the privilege of interacting with Appu George only a few times, but his kindness and positivity left a lasting impression on our family.

Before my son Kartikeya's surgery in June 2025, Appu stayed in touch with my husband, regularly checking on Kartikeya's condition and offering much-needed moral support. Later, when Kartikeya spoke with him, Appu encouraged him like a friend and an elder brother, inspiring him to stay positive and embrace life with courage. Knowing Kartikeya's love for wildlife photography, he even invited him to visit Kumarakom Bird Sanctuary together.

Today, only memories remain. Appu was a noble, kind-hearted, and vibrant soul who touched countless lives through his compassion and generosity. Though his journey was far too short, he lived with purpose and leaves behind a legacy that will continue to inspire CHD parents and CHD warriors for years to come.

Rest in peace, Appu. You will always be remembered with gratitude and affection. ❤️

-Meena Gupta
(CHD parent)

Appu Sir had a wonderful nature—humble, helpful, caring, and loving. Words are not enough to describe the kind of person he was.

Appu Sir was like an elder brother to me. Whenever I talked to him, he always shared new ideas. He was constantly thinking about doing something new, making new plans, and looking ahead to the next step. He always had a positive mindset and inspired others with his optimism.

He never let anyone feel that he was ill. He lived a healthy lifestyle, stayed happy, remained active, and managed his daily routine and work with dedication. Whether it was his personal life or professional responsibilities, he handled everything with energy and determination. He inspired others by facing every challenge with strength, courage, and a smile.

His life is truly inspiring. I believe that a fighter never truly leaves us. He remains alive in our hearts forever, and he always will.

-Qazi Nishat Afza

To many, he was a guiding light, a CHD warrior who transformed his own lifelong battle into a shield and a source of strength for others. Whenever a family felt lost, scared, or overwhelmed by a CHD diagnosis, Appu was there to offer wisdom, a listening ear, and the motivation to keep going. He fought relentlessly for the rights and recognition of our community, proving that a diagnosis does not define us, but rather shows how strong we can be. His legacy will forever be etched into the hearts of every family he helped. You fought long, you fought hard, and you left this world better than you found it. With a heavy heart we say goodbye to Appu. Thank you for all your support, Appu.

-Sindhu, Shriya



Everyone at Global ARCH is so saddened to hear about Appu's passing. He was an enthusiastic and devoted member of our community, and we always looked forward to seeing him at our monthly Leaders' Forum. He has accomplished so much in the CHD community in India – he will never be forgotten. He was a gentle man with a heart of gold – we need more people in the world like Appu. These are just a few comments we received on our WhatsApp community chat when his passing was announced. He was very dearly loved.

-GLOBAL ARCH

Appu K George. He was an absolute warrior. Sending our heartfelt condolences, thoughts, and prayers to his grieving family.

- Farhan Ahmad
Pakistan Children's Heart Foundation

A big loss of such a beautiful soul, for our community and across the world. Thoughts and prayers with Appu's family, friends & heart family. May you rest in peace Appu.

-Rajwat Kaur Singh
The Children's Heart Federation, UK

We lost a warrior that can never be replaced.

-Tendai Moyo
Brave Little Hearts, Zimbabwe

You made such a difference Appu, may you rest in peace. Thinking of Appu's family and friends at this difficult time.

- Michelle Woods
Somerville Heart Foundation, UK

Very sad to hear about Appu's passing. A big loss. Rest in peace, Appu.

- Amaya Saez
Fundacion Menudos Corazones, Spain

Condolences to the family. May our Creator put patience and peace in the hearts of his family and all that knew him.

- Raadhiyah Matthews
Brave Little Hearts South Africa

God bless to his family in this difficult time, and also to the congenital heart disease community in India, rest in peace Appu.

-Cecy Ramirez
Fundacion Corazones Luchadores, Chile

I can't believe it! Such a beautiful heart! He will be missed.

-Belen Blanton
Estrellita de Belen Foundation, Venezuela

Deepest condolences to the family. A great heart warrior indeed.

-Theresa Gnanakkan
IJN and CHD Malaysia

One of my favourite people to see at our online Leaders' Forum. He was always so cheerful and sweet. I wish I'd had the opportunity to meet and thank him in person.

-Shelagh Ross, Global ARCH co-founder, Canada

You were always there for Yusra whenever she needed it the most. Every doctor's appointment, every follow up, you were the one checking in, asking how she was doing, making sure she was never facing it alone. You did this quietly, without ever expecting anything in return. You never truly realised how much you meant to us, the heart families. You were more than a friend to us. You were a source of strength, a reminder that no one in this fight walks alone. You will stay with us, in every heartbeat, in every story we tell, forever and always.

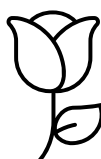
- Tarana A Tabassum
Dhaka (Bangladesh)



"Born with a heart defect, raised with extraordinary strength."

FOREVER IN OUR HEARTS

OUR BELOVED APPU



**"Not every heart beats perfectly, but every heart
deserves a chance to beat." ❤️**

A Journey Beyond the Diagnosis

By **Qazi Nishat Afza** | CHD Warrior



Afza Nishat Qazi

Living with Adult Congenital Heart Disease (ACHD) is not only a physical journey but also an emotional and social one. When these children grow up, they face even greater challenges — challenges that extend far beyond hospital visits, medications, and medical appointments. The journey encompassing mental health, relationships, marriage, and parenthood become incredibly difficult when one must confront hurdles created by people and a society that refuses to understand.

There are so many misconceptions. Society often assumes that if you are unwell — if you are an ACHD patient or have any illness — you cannot start a family or get married. Even in a relationship, a partner may believe you are incapable because you are not perfectly healthy. But a person's worth should never be judged this way. An illness does not define whether someone is perfect or not.

True perfection is not about perfect health — it is about good character, the capacity to love, and the strength to nurture.

In real world, no human being is ever truly perfect; everyone carries some flaw or another. A good human being is shaped by good behaviour, right understanding, positive thinking, the ability to maintain relationships, and the way they treat others. Being a good human being is far more important than being a so-called perfect person.

The Impact on Mental Health

Adults living with CHD may experience emotional distress due to anxiety, stress, fear of future health-related complications, and the burden of prolonged medical procedures. Constant exposure to negative social attitudes can deeply affect mental health. When people repeatedly hear that they cannot marry, cannot have children, or cannot live a normal life, they may begin to doubt themselves — leading to anxiety, depression, low self-esteem, social withdrawal, and feelings of isolation.

That is why mental health support is an essential part of adult CHD care. Patients need encouragement, counselling, peer support, and opportunities to connect with others who understand their experiences.

Marriage, Motherhood, and Misconceptions

Another common misconception particularly affects women with CHD. Society often assumes that if a woman may face challenges during pregnancy, she should not marry. This is a deeply flawed mindset that needs to change. Marriage is much more than the ability to become pregnant; it is a partnership built on companionship, emotional support, trust, and shared goals. While some women with CHD can safely become pregnant under specialist medical supervision, others may be advised against pregnancy due to health risks. This does not mean they cannot have happy marriages or fulfilling family lives. Women with CHD can certainly become mothers — surrogacy and adoption are excellent paths.

Surrogacy

In certain cases of CHD, pregnancy places immense strain on the mother's heart, which can be life-threatening. Surrogacy eliminates this significant risk. Through gestational surrogacy, it is possible to have a biologically related child using your own and your partner's genetic material, without putting your health at unnecessary risk. Important considerations include obtaining medical clearance from both a cardiologist and a fertility specialist, genetic counselling, and understanding the legal framework governing surrogacy in India (the Surrogacy Regulation Act mandates altruistic surrogacy only).

Adoption

If surrogacy or IVF is not safe for your health, adoption is a wonderful option. It is not the blood relationship that defines family — it is the emotional bond formed through love, care, and affection.

No illness should be viewed as a barrier to marriage, relationships, parenthood, education, or a successful career.

A medical condition is only one part of a person's life. Many people living with chronic conditions such as ACHD lead happy, fulfilling lives. A medical condition does not define a person's abilities, worth, or potential.



Nishat & Family

मुश्किलों से लड़कर आज भी खड़ा हूँ

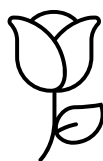
By **Qazi Nishat Afza** | CHD Warrior — Original Hindi Poem

जिसमें मुश्किलें ना हों
 वो हौसला ही क्या!
 जो टूटा ना हो
 वो सब्र ही क्या!
 जिसका इम्तिहान दिया ना हो
 उस पर तेरी हिम्मत का जवाब ही क्या!
 उन आजमाइशों का क्या
 जिनसे तू गुज़रा ना हो
 तू आज अगर डर गया तो
 इतनी मुश्किलों के सामने खड़े रहने का फायदा ही क्या!

Qazi Nishat Afza

— English Translation —

*What is courage if it has never faced hardship?
 What is patience if it has never been broken?
 How can anyone measure your strength if it has never been tested?
 What are trials worth if you have never walked through them?
 If you choose fear today,
 then what was the purpose of standing tall
 through every challenge that brought you here?*



Strength Beneath the Scar

By **Bhavani Sekar** | CHD Warrior, Chennai, Tamil Nadu



Bhavani Sekar

My name is Bhavani Sekar, and I am a CHD warrior from Chennai, Tamil Nadu. I was born with a complex form of Congenital Heart Disease — Tricuspid Atresia, along with ASD and VSD. When I came into this world, doctors told my parents something no family is ever ready to hear that I might live only for ten days. But I am still here.

In those early days, doctors advised my parents to take extreme care of me. Even a simple cold or cough could become serious. At that time, in 1993, medical options were limited. When my parents took me for treatment, doctors said I was too small and fragile to undergo surgery. My life began not with certainty, but with caution — not with guarantees, but with hope.

I have an elder brother who is completely healthy. Watching him grow normally made me slowly realise that my life was different. Even small movements left me breathless. My nails would turn blue, and my lips would become dark — visible signs that something inside me was not the same as others.

Though my parents were not highly educated, they did everything they could to care for me. When I was around eight years old, they took me to Sri Sathya Sai Institute of Higher Medical Sciences in Bangalore with hope for treatment. We were told we would be contacted for further steps, but that call never came. We waited with hope, but silence was all we received.

As years passed, I continued my education, travelling to school by bus and learning to manage my condition in small ways. I was a good student, and my father supported me with love and care. Physical education classes were always the hardest part of school life.

'You may become a wife... but not a mother.' Those words shattered my world in ways no one could see.

At the age of 17, breathing itself became difficult, and I underwent Glenn Shunt surgery at Apollo Children's Hospital, Chennai. Life after surgery was not easy. Blood thinners caused severe menstrual struggles, but I did not stop my education. I completed my BA in English Literature through distance education in 2014.

Facing Society's Gaze

As years passed, my parents wished for my brother to get married. That was when another painful phase began. During the search for a bride, people questioned my health too. Suddenly, my CHD became a topic for society to discuss, judge, and whisper about. With courage, I finally created a matrimony profile. I chose honesty. I openly mentioned my CHD condition and shared that adoption may be the path for my future motherhood journey.

Finding Purpose in Small Things

There were days when thoughts about my health, future, marriage, and uncertainty slowly pushed me into depression. But somewhere in that darkness, I started holding on to small things to heal myself. I began learning tailoring, embroidery, gardening, cooking, editing, and many new skills. These hobbies did not remove my pain completely, but they helped me breathe again. They gave me purpose during difficult days and reminded me that even when life feels heavy, I am still capable of creating beautiful things.

Sometimes survival is not just about medicines or surgeries.

Sometimes survival is finding small reasons to live again.

***Sometimes survival is not just about medicines or surgeries.
Sometimes survival is finding small reasons to live again.***

Honestly, CHD needs more awareness in society. People often see congenital heart disease as just a “heart problem,” but they do not understand the lifelong physical, emotional, social, and financial struggles behind it.

Many adults living with CHD silently battle oxygen issues, surgeries, medications, fear about the future, marriage struggles, and mental health pain. What people like us truly need is understanding, support, and suitable job opportunities that match our health conditions. Not every CHD warrior can handle physically exhausting work, yet we still desire independence, dignity, and confidence. Sometimes, a safe job opportunity and a little kindness can change an entire life for someone silently struggling with CHD.

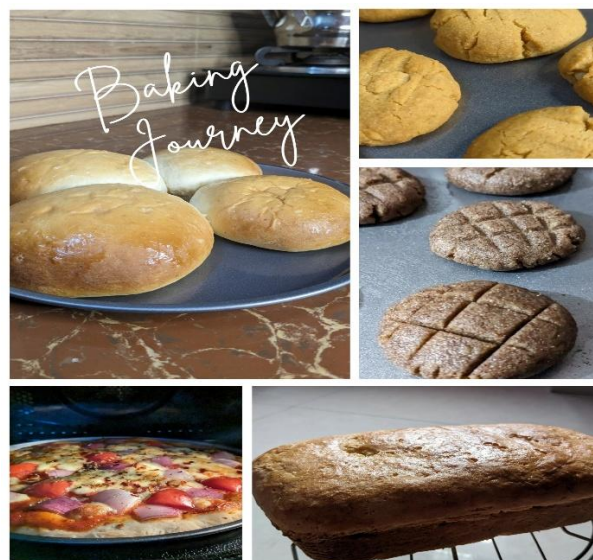
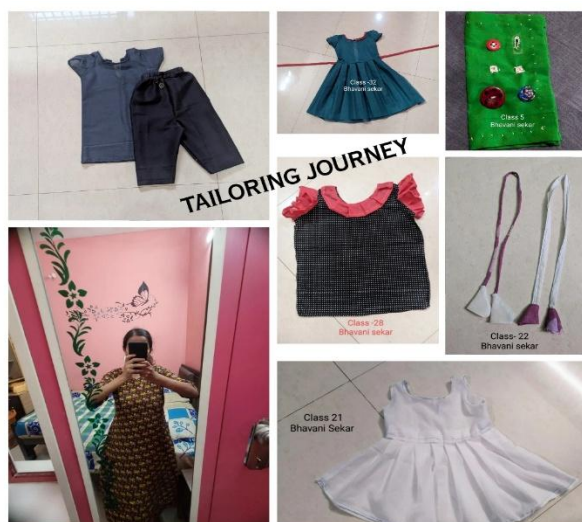
Later, I connected with people like me — fellow heart warriors living with CHD. Listening to their stories, sharing our struggles, and supporting one another online slowly helped me heal. In an ableist society, living as a CHD warrior is not easy. Many of us silently face judgment, loneliness, fear about the future, and emotional exhaustion. That is why support groups and safe communities are so important. Sometimes, talking to someone who truly understands your journey can give you strength to keep going.

We may carry scars in our hearts, but together we remind each other that we are not alone.

Later, I connected with fellow heart warriors living with CHD. Listening to their stories, sharing our struggles, and supporting one another online slowly helped me heal. We may carry scars in our hearts, but together we remind each other that we are not alone.

Living with CHD means constantly standing between hope and fear. Every medical decision feels heavy — not only for me, but for my family too.

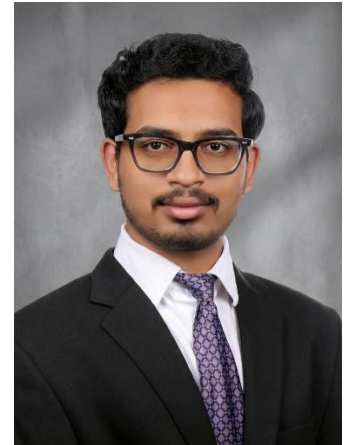
Hobbies



"CHD awareness begins with understanding, compassion, and support."

Beating Different

By **Siddharth Lokireddy** | CHD Warrior & Medical Student



Siddharth Lokireddy

There I was sitting in the lecture hall in my medical college, and suddenly everything clicked in place. It all started to make more sense. The lecture was on coarctation of aorta, the very defect that was present right there in my own chest. It felt special to learn in detail about something that I've lived my entire life with, an opportunity not many others get.

I loved playing football in my school and would never miss a session no matter what the reason. But for a few months, my legs have been going numb after a few minutes of play, and I would frequently fall because the sensation was lost in my legs and I didn't know how they were positioned and what was happening to them. For me, as a 9th grade student, nothing seemed wrong, and it felt like this was one of the things that would subside by itself and I didn't even think about how this could be medically related. Then came the vacation that changed everything. I couldn't complete a simple trek up a hill because of how breathless I got, and it was my cardiologist in India, Dr. Nitin Rao, who had been watching over me ever since my second surgery, who first flagged the need for closer attention. I had always taken one pill of low dose aspirin every day before bed but never really questioned it. Here I was, now mature enough to understand what was happening to me and what the consequences could be.

I was born with a congenital heart defect, a coarctation of the aorta. I was lucky enough that my pediatrician got suspicious of no pulse being felt at my lower limbs and diagnosed me immediately. I had three surgeries in the US, where I was born. One when I was just 2 days old, when the size of the heart is as small as the nail on our thumb. The next when I was 18 months old, and the other when I was 14 years old, in 9th grade, where this story started. All three of my surgeries were done at Mercy Children's Hospital, Iowa, USA, by the same surgeon, Dr. Hockmuth.

The third surgery was when it really hit me that I had a serious heart defect. I will be forever grateful to my parents for the way they took care of me in the months that followed. Immediately after surgery my first breath felt like my ribs were cracking, I had to be rehabilitated to walk again gradually after a few days, and I developed a migraine problem due to changes in my body after the surgery.

The psychological weight of this was immense, especially since I wasn't young anymore to not think about the complexities associated with my condition and living with it. I never knew if I would be able to play my favorite sports again, without having a second thought about diving for the ball or overexerting myself. There was a level of uncertainty about how I would progress forward from this point. Would I spend my life constantly worrying about my health, or would I learn to carry it quietly and move forward? My daily dose of aspirin helped a lot in this regard. I would not think about my condition for the entire day, but it would come nighttime when it was time to take my medication, and I would be subtly reminded that I still live with this condition. It doesn't bring me sadness at that point to be reminded about it but provides me with a hook to bring me back to my roots and gently prompt me to never forget why I was working towards my goals.

Our hearts beat different, but that never stopped us from reaching great heights or dreaming to achieve what nobody else dares to reach for.

The third surgery was when the reality of my condition truly struck me. My first breath after the operation felt as though my ribs were cracking. I had to be gradually rehabilitated to walking again, and I developed migraines due to changes in my body following surgery. The psychological weight was immense.

From Patient to Doctor

Learning to live with these problems rather than waiting for them to disappear was perhaps the most important thing my condition has ever taught me. I decided to become a doctor after having been through so much at a young age and wanted to contribute to the medical community, who did so much for me. I didn't shy away from my problem. I embraced it. I never let it be a hindrance to what I do, but I was mindful of my actions all the same. My heart problem wasn't a "problem" for me, it became my strength. It had shown me life's worst, but I did not break. Once I realized that I had this resolve in myself, I was thankful for everything that had happened to me up to this point.

Today I am an All-India Ranker of 2546 in the NEET exam, having studied through countless episodes of migraines, regular visits to the doctors every few months and above all having the unshakeable dream of becoming a doctor. This resulted in me doing my medical degree in one of the most premier institutes in the country and am preparing to write further exams to become a surgeon, just like the one who saved my life not once, not twice, but three times. He is truly my hero. Would I succeed in my dream of becoming like my hero, only time would tell.

Becoming a doctor when you were a patient for the same disease that you're trying to treat holds a different view of life that not many others get to experience. For the first time I found myself on the doctor's side of the bed, after a lifetime of being on the other side. It puts you in the perspective of the patient, where I've been countless times, and this makes you a kinder, more compassionate doctor who truly understands the view of those who are entrusted in our care.

Our hearts beat differently, but that never stopped us from reaching great heights or dreaming of achieving what nobody else dares to reach for. Living with a cardiac complexity gives us a different perspective on life and how to cherish it, finding inner strengths which we never knew we had. No human is limited. Never let your defects define what you can achieve, they are only there to remind you of what you can endure and emerge from, **victorious**.

No human is limited. Never let your defects define what you can achieve — they are only there to remind you of what you can endure and emerge from, victorious.



Playing Golf and becoming a doctor



Siddharth Lokkireddy & His Doctor

My Journey With Congenital Heart Disease: A Story of Survival, Strength, and Self-Discovery

By **Ketaki Raj (Keshu)** | CHD Warrior, Chandigarh



Ketaki Raj

Keshu (Ketaki Raj) is a 25-year-old Astrologer, Numerology Teacher, and Instagram Content Creator from Panipat, Haryana, currently living in Chandigarh for medical care. Diagnosed with a congenital heart condition at one month of age, she faced numerous health challenges that prevented her from continuing formal education beyond the fifth grade. Undeterred, she pursued self-learning in Astrology and Numerology and built a successful career teaching and guiding others. She underwent staged Fontan surgeries in 2012 and 2015, completing the available treatment for her condition. Today, she inspires others through her resilience, knowledge, and positive outlook on life.

I was born with a congenital heart disease — a condition discovered when I was just one month old. My family noticed unusual breathing sounds during sleep and a very fast heartbeat, after which doctors confirmed my diagnosis. Because I was severely underweight and physically too weak, surgery could not happen on time. The risk was too high. Many doctors were hesitant, saying survival was nearly impossible.

For years, I lived with a heart that struggled every single day. By the time I turned eleven, one doctor finally agreed to take my case. He said: 'Let's try. There is a possibility she will survive.' That was the first time anyone had spoken with even a little hope. My first surgery happened when I was eleven years old. When I turned fourteen, the second-stage Fontan procedure was completed with hope that this time my heart would function better.

***Surgery does not solve everything. It only gives you a chance.
What you do with that chance — how you live with care,
discipline, and awareness — that is what truly matters.***

After surgery, life did not become normal. In many ways, it became even more demanding. I had to follow strict precautions every single day: no heavy lifting, no physical or emotional exhaustion, difficult travel, mandatory eight hours of sleep, and careful management of food and digestion. Mental and emotional health can affect the heart more than most people realise.

Life Beyond Illness

My journey taught me that even if the body has limits, talent has no limits. Dreams have no limits. Potential is not defined by a medical condition. Because of my health condition, I was unable to continue regular schooling beyond the fifth class. However, I pursued studies in Astrology and Numerology. Today, I work as an Astrology Teacher, Numerology Teacher, and Instagram Content Creator, known on social media as Ketaki Raj.

Today, when I look back, I do not see only struggles — I see survival. I see strength. I see a life that refused to give up.

You may have limitations, but you also have possibilities. You can still achieve, still grow, still shine. Your life is not defined by your illness — it is defined by your courage.



-Ketaki Raj & her mother

"A heart may be born different, but its capacity for courage is limitless."

साँसों से पहले सपने।

By **Ketaki Raj** | CHD Warrior — Original Hindi Poem

ख्वाबों को पूरा करने की चाह तो है,
पर साँसें उतनी ही कम हैं।
ऊँची उड़ान भरने की इच्छा तो है,
पर पंख ही नहीं हैं।

कुछ बड़ा करके दिखाने की आकांक्षा तो है,
पर परिस्थितियों की अनुमति नहीं है।
अपनी एक पहचान बनाने की अभिलाषा भी है,
पर हौसलों की कमी है...

बस अब इतनी ही प्रार्थना है कि
साँसें पूरी होने से पहले ख्वाबों को परिस्थितियों का साथ मिल जाए,
और अपनी पहचान बनाने के लिए
हौसलों को थोड़ी-सी उड़ान मिल जाए।

— English Translation —

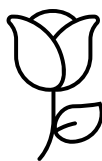
I yearn to fulfil my dreams, yet breath runs so short.

I wish to soar to great heights, yet I have no wings.

I aspire to achieve something great, yet circumstances do not permit.

I long to carve my own identity, yet courage seems to be lacking...

***All I pray now is that before these breaths run out, my dreams find the support of
circumstance, and to build my identity, may my courage be granted just a little
flight.***



Dating and Congenital Heart Disease: Navigating Love with a Strong Heart

By **Nikhil Shah** | CHD Warrior, Amravati



Nikhil shah

Romantic connection is a fundamental human need. For the lakhs of adults living with congenital heart disease (CHD), pursuing love and intimacy is entirely possible and deeply worthwhile. Yet the journey comes with its own set of unique challenges. I'm writing this essay after exploring why dating matters for CHD adults, what challenges I faced, and most importantly - practical strategies to navigate those challenges with confidence and joy.

Why should you date if you are an Adult with CHD?

Emotional wellbeing and mental health. Loneliness and social isolation are known risk factors for worsening health outcomes, including in cardiac patients. Romantic relationships offer companionship, emotional validation, and a sense of belonging that directly supports mental and physical health. Studies consistently show that being in supportive relationships helps manage chronic illness better.

Identity beyond illness. Many CHD adults have spent significant portions of their lives defined by hospital stays, medications, and medical procedures. Dating and romantic connection offer a powerful reminder that they are not just patients, they are multidimensional people with personality, humour, dreams, and desires. A fulfilling relationship can be one of the most affirming experiences of one's life.

Building a support system for the future. Life with CHD often involves ongoing medical management, follow-up appointments, and occasional health scares. A loving, informed partner can become an invaluable part of one's support network, helping to manage medical appointments, advocate in healthcare settings, and provide emotional grounding during difficult periods.

Shared joy and quality of life. Beyond practical support, love simply makes life richer. Travel, shared meals, laughter, celebrating milestones, all of these experiences are available to CHD adults,

and sharing them with a partner amplifies their meaning. Dating opens the door to those shared chapters.

Legacy and family planning. Many CHD adults wish to build families of their own. Dating is the natural first step toward that goal, and while pregnancy and parenthood require careful medical planning for some CHD individuals, many go on to have healthy families with the right guidance.

Challenges & Solutions

1. Disclosure Anxiety

One of the most universal concerns is figuring out when and how to tell a potential partner about a heart condition. Too early and it can feel like leading with a medical history rather than a personality. Too late and there's a fear of deception or rejection after emotional investment has deepened.

On Disclosure

Prepare your "disclosure script" in advance. Rather than figuring out what to say in the moment, think through a simple, honest explanation of your condition that feels natural to you. Practise saying it out loud, to a friend, in a mirror, or even recording yourself. The more fluent you become at talking about your heart, the less charged the moment will feel.

Choose a calm, private setting. Disclosure ideally happens in a relaxed one-on-one setting, not in the middle of a noisy restaurant or on a first date when nerves are already high. A quiet walk or a low-key evening at home tends to work better than a formal setting.

Frame it as information, not confession. The tone you use when disclosing matters enormously. Approaching it with "I just want to be open with you about my health" rather than "I need to tell you something serious" sets a very different emotional tone. Present it as a normal part of getting to know each other.

Have educational resources ready. Some partners want to learn more after hearing about CHD. Having a simple website, or even a short explanation ready to share can help a curious partner understand without overwhelming them.

Give them time to process. After disclosing, give your partner space to absorb the information without demanding an immediate emotional response. Let the conversation breathe.

2. Visible physical differences.

Surgical scars on the chest, a pacemaker or defibrillator bulge under the skin, or a bluish tint to lips or fingernails can feel like immediate conversation stoppers, particularly in contexts where physical appearance is prominent.

On Physical Appearance and Scars

Reclaim your scars as part of your story. Many CHD adults have found that shifting from shame to ownership of their scars is transformative. Scars are evidence of survival, strength, and medical courage.

Practice exposure gradually. If body confidence is an issue, gradually becoming more comfortable with your physical appearance in lower-stakes situations like beach trips with friends or casual pool outings can reduce the anxiety around being seen by a romantic partner.

Talk about it before it comes up. If you have a prominent scar or device, proactively mentioning it in a matter-of-fact way removes the awkwardness entirely and gives you control of the narrative.

3. Reduced stamina and physical limitations.

Many CHD adults experience reduced exercise tolerance, breathlessness with exertion, or fatigue that affects daily activities. This can create anxiety around active dates, hiking, cycling or situations where keeping up physically with a partner feels difficult.

On Physical Limitations and Active Dates

Suggest date formats that suit your energy levels. You don't have to pretend to be someone who loves five-hour hikes. Suggest dates that genuinely appeal to you and align with your physical comfort like gardening, a museum visit, a long drive, a picnic, a film night. These can be just as romantic, often more memorable, and reflect your real personality.

Be honest early about activity preferences. Saying *"I prefer lower-key activities, I love exploring urban areas, trying new restaurants, and long drives with loud music"* (I mean who doesn't love long drives with loud music?). This sets accurate expectations without requiring a medical explanation at all.

Know your limits and plan around them. If you know that evenings are harder than afternoons due to fatigue, suggest daytime dates. If you need rest time after exertion, build that into plans without shame.

4. Concerns about intimacy.

Questions about whether physical intimacy is safe, how to address breathing difficulties, comfortable positioning, or energy levels can cause significant anxiety. Partners may misinterpret caution as disinterest, and CHD adults may feel embarrassed discussing these topics.

On Intimacy

TALK TO YOUR CARDIOLOGIST FIRST. If you have concerns about physical intimacy, especially around exertion, breathlessness, or device safety, have a direct conversation with your cardiac team. Many cardiologists are experienced at addressing these concerns and can give you clear, evidence-based guidance. Be informed, before walking into intimacy, it reduces anxiety enormously.

Communicate openly with your partner. Most partners would rather know your preferences and needs than accidentally make you uncomfortable. Framing conversations around what feels good and what doesn't BUT without turning it into a medical briefing.

Start slow and build comfort together. There is no rush. Emotional intimacy, trust, and physical comfort naturally build over time, and giving that process space to unfold reduces pressure significantly.

5. Fear of being a burden.

A deep and persistent worry for many is that their health needs, whether medical appointments, hospital admissions, medication management, or lifestyle restrictions will feel burdensome to a partner. This fear can lead to pulling away from otherwise healthy relationships.

On Fear of Being a Burden

Challenge the narrative directly. Being a burden is a story, not a fact. Most people in loving relationships take turns needing more support at different times, through illness, job loss, grief, or stress. Your health needs are not exceptional in the context of a full life together.

Be specific rather than exaggerating. Instead of vaguely worrying about being *"too much"*, think concretely: what actual support might you need, and how often? Often, the reality is much more manageable than the anxiety suggests.

Discuss roles and responsibilities openly, in time. As relationships deepen, honest conversations about what you might need or not need during hospital stays or health events, give partners clarity and dispel the fear of the unknown.

6. Future uncertainty.

CHD adults may face questions about life expectancy, the need for future surgeries, or pregnancy complications. These can create hesitation about investing in a relationship, and anxiety about how to discuss them with a partner without creating fear or driving them away. (*this one happens too often*)

On Future Uncertainty and Family Planning

Consult an ACHD specialist before these conversations go too deep. Adult Congenital Heart Disease (ACHD) specialists and cardiac geneticists can provide detailed, personalised information about reproductive options, pregnancy risk (if applicable), genetic transmission likelihood, and long-term prognosis. Being armed with accurate information means you can have these conversations with a partner from a place of knowledge rather than vague anxiety.

Acknowledge uncertainty rather than predicting doom. NO ONE - CHD or not, NO ONE can predict their health future with certainty. Framing conversations around *"here's what I know, here's what's uncertain, and here's how I manage it"* is honest without being fatalistic.

Explore all family-building options. For those with higher-risk pregnancies, options such as adoption, surrogacy, or fostering are meaningful, fulfilling paths. Knowing these options exist removes the sense that CHD automatically closes doors.

7. Past relationship trauma.

"Some" CHD adults have experienced painful rejection specifically because of their condition, leading to self-protective behaviour, trust issues, and a reluctance to open again.

On Past Relationship Trauma

Acknowledge that the pain was real and valid. Being rejected because of a heart condition is a particular kind of hurt. It touches not only romantic rejection, but also something deeper, the fear that your health makes you unlovable. Give yourself permission to feel that pain rather than rushing to move past it. At the same time, do not let one person's response become your belief system. Someone who could not accept your CHD was simply not equipped to be your partner. Their limitation is not your life sentence, and one painful experience or even several - does not define how others will see you.

Seek the right support to process and heal. A therapist familiar with chronic illness can help you recognize protective patterns that may have developed after being hurt, such as emotional withdrawal, over-explaining your condition, or pushing potential partners away before they have the chance to leave. Beyond professional support, connecting with the CHD community through support groups, peer mentoring, or patient networks can be equally powerful. Hearing from others who have faced similar challenges and found meaningful relationships can remind you that your past experiences do not determine your future.

Give yourself time and give new partners a fair chance. Healing from relationship trauma has no fixed timeline. Some people feel ready to date again relatively quickly, while others need months or even years of personal healing, and both paths are valid. What matters is returning to dating when the past no longer holds more power than the present. When you do, try to notice moments when you may be reacting to a new person through the lens of an old hurt. If someone responds to your disclosure with kindness, understanding, and curiosity, allow yourself to receive that.

8. Navigating dating apps and online profiles.

Deciding whether to mention CHD in a dating profile and how? is a genuine dilemma. Being too upfront may attract pity or deter matches; not mentioning it may feel inauthentic.

On Dating Apps and Online Profiles

You do not have to disclose in your profile. A dating profile is a highlight reel, not a medical form. Most CHD adults find that disclosing in person, once a genuine connection is established, works better than leading with it online.

If you choose to mention it. JUST DON'T - *Tried, test and failed (zero right swipes)*

Use your profile to reflect who you are. Lean into your real personality, interests, and values. The right match is attracted to you, and the more authentically you present yourself, the more compatible your matches will tend to be.

How to Stay Positive

Stay connected with CHD community. Connecting with other CHD adults, through organisations, online forums, or local patient groups, provides access to people who genuinely understand the dating experience you're navigating. Hearing success stories from others who have found love is among the most potent antidotes to hopelessness.

Work with a therapist, ideally one familiar with chronic illness. Therapy is not just for crisis. A skilled therapist can help you work through disclosure anxiety, body image concerns, relationship patterns rooted in illness-related trauma, and fear of the future. Cognitive Behavioural Therapy (CBT) has strong evidence for reducing health-related anxiety.

Keep a gratitude practice. Actively noticing and recording what is going well, a great conversation, a moment of confidence, a date that felt easy, trains the brain away from its natural tendency to fixate on fears and setbacks.

Reframe rejection healthily. Rejection is painful for everyone, but it is rarely about CHD alone. Most people experience multiple rejections before finding the right match, and a partner who walks

away because of a heart condition has revealed they are not the right person, which is valuable information, not a verdict on your worth.

Set meaningful goals beyond dating. A rich, engaged life with hobbies, friendships, career pursuits, creative projects, and travel, makes anyone more interesting and, crucially, makes the absence of a romantic partner feel less like a wound. Fullness attracts.

Celebrate every milestone, big and small. First dates, honest disclosures, moments of physical confidence, vulnerable conversations, each of these is genuinely brave for a CHD adult navigating a world that does not always make space for their experience. Acknowledge and celebrate them.

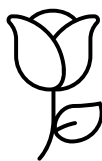
Remember that your condition is one chapter, not the whole book. You are witty, thoughtful, resilient, creative, ambitious, funny, caring, all those things existed before, alongside, and independently of your heart. The person who falls in love with you will fall in love with all of it.

Conclusion

Dating with congenital heart disease is not about managing a disadvantage, it is about bringing your whole, extraordinary self into connection with another person. The challenges are real, but so are the tools to navigate them. With honest communication, practical preparation, professional support, and a commitment to your own self-worth, CHD adults can build the same deeply fulfilling romantic lives that everyone deserves. The heart, after all in every sense, is made for love.

to bring me back to my roots and gently prompt me to never forget why I was working towards my goals.

Our hearts beat different, but that never stopped us from reaching great heights or dreaming to achieve what nobody else dares to reach for.



The pillars of unwavering Strength 'The Parents'



In frame

Dr. Suchismita Haldar and Ethan, Nikhil Shah & family, Krishna & His father, Vivaan & family, Adidev Reddy & his mother, Amritha & family



In frame

Araf Ahmad & family, Arti and her son, Pooja Sharma and her daughter, Kartikeya and Meena Gupta, Kaushiki & family, Jaarul Jangid & family

A Journey Written in Faith

By **Sajani Nair** | CHD Parent

There are days in life that divide time into two parts — before and after.

For me, that day arrived quietly, hidden behind medical terms I did not yet understand and decisions I was not prepared to make. One moment I was the mother of a happy little child; the next, I was standing at the threshold of a journey that would redefine motherhood itself.

The years that followed became a blur of hospital corridors, overnight train journeys, crowded airports, waiting rooms, and consultations. We travelled from one city to another seeking answers, carrying reports thicker than storybooks and questions that never seemed to end.

The greatest burden was not the travel or the expenses. It was the responsibility of making decisions no parent ever wants to make. How does one sign a consent form when the person on the operating table is your own child? How does one smile and reassure a three-year-old when your own heart is breaking?

The follow-ups became a way of life. Echocardiograms, tests, reviews, medicines, precautions. Every appointment brought hope, but also anxiety. Every fever triggered panic. Every cough stole sleep.

Raising a Child Wrapped in Invisible Caution

While other parents encouraged adventure, I found myself calculating risks. Social gatherings, sports, school trips, infections, seasonal illnesses—everything carried a question mark. During the pandemic, that uncertainty multiplied. Fear became a constant companion. Each day felt like a battle between protecting him and allowing him to live a normal childhood.

As he grew older, the decisions became more complex.

There were dreams that had to be gently redirected. Activities that had to be avoided. Difficult conversations no parent wishes to have. Watching a child discover that some paths may not be open to him is a pain that leaves no visible scars but lingers for years.

Education brought another set of challenges. Institutions often saw reports before they saw the person. Some offered support. Others offered conditions, warnings, and doubts. More than once, I wondered whether the world would ever look beyond a diagnosis and see the capable, determined young man standing before them.

Yet he kept moving forward.

And so did we.

There were days when family members questioned our choices. Days when fear whispered that we were taking unnecessary risks. Days when sending him away from home felt impossible. But courage is not the absence of fear. It is acting despite it.

Courage is not the absence of fear. It is acting despite it.

The Gift of Perseverance

Slowly, the child I had once carried into hospitals began carrying his own responsibilities. The young boy who had spent years under medical supervision learned to navigate life independently. He pursued his education, built his confidence, and eventually stepped into the professional world. The future is yet enshrouded in his lifelong conditioning. His choices of having social circle and family forward are still as vague as can be. Yet he is the anchor of all that as a mother I can dream of.

Looking back now, I realize that this journey was never only about illness or treatment. It was about learning to live with uncertainty. It was about discovering reservoirs of strength I never knew existed. It was about choosing to hope repeatedly, even when circumstances offered little certainty.

Most of all, it was about faith.

Faith that tomorrow would be kinder than today.

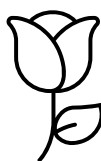
Faith that every setback would pass.

Faith that God was walking beside us even when the road ahead was invisible.

The journey was rarely easy. At times it was exhausting, lonely, and overwhelming. But through every hospital visit, every difficult decision, every sleepless night, and every unexpected blessing, one truth remained constant:

We were never walking alone.

And today, when I see how far he has come, I know that every tear, every prayer, every mile travelled, and every act of courage was worth it.



Raising a Heart Warrior: A Mother's Journey Through Congenital Heart Disease

By **Pritisudha Sharma** | CHD Mother, Kolkata



Pritisudha Sharma

The day my daughter was diagnosed with congenital heart disease (CHD), my world changed forever.

Like most parents, I had imagined her first steps, her first day of school, her dreams and ambitions. I never imagined that before she could even understand the world around her, she would have to fight battles that many adults would find overwhelming. Today, at just three years old, she has already undergone two open-heart surgeries. She carries scars on her tiny chest, but more importantly, she carries a strength that inspires everyone around her.

As her mother, I have often wondered whether I am raising her or whether she is teaching me how to be brave.

Learning a New Language: The World of Paediatric Cardiology

One of the first realities that hit us after the diagnosis was that we had entered an entirely new world—a world filled with medical terminology, investigations, surgeries, medications, and appointments. Initially, words like echocardiogram, catheterization, ventricular function, arrhythmia, oxygen saturation, pulmonary artery pressure, and valve regurgitation sounded like a foreign language. Every consultation felt overwhelming. I would sit with a notebook, trying desperately to understand what the doctors were discussing about my child.

Gradually, I realized that as parents of a child with CHD, we often become accidental students of pediatric cardiology.

We learn how the heart works. We learn the anatomy of our child's unique heart. We learn to read reports, monitor symptoms, understand medications, and recognize warning signs. We learn which questions to ask during consultations. We learn that surgeries may not always be "fixes" but sometimes part of a lifelong journey.

After the diagnosis comes a process that most CHD families know well: multiple tests and scans, frequent visits to paediatric cardiologists, discussions about surgeries or interventions, monitoring

growth and development, learning about medications, tracking exercise tolerance and symptoms, and long-term follow-up plans.

What once felt terrifying gradually becomes part of daily life.

While I never wanted to learn any of this, knowledge became my greatest source of strength.

Understanding my daughter's condition helped me advocate for her, make informed decisions, and feel less helpless during uncertain times.

The Worries That Never Truly Leave

People often think that once surgery is over, life returns to normal. The truth is more complicated. CHD parents live with a unique kind of worry that never completely disappears. It changes shape over time, but it remains present. We worry before surgeries. We worry after surgeries. We worry during routine follow-ups. We worry when our child catches a simple cold. Every fever raises questions. Every complaint of fatigue catches our attention. Every unusual symptom sends our minds racing. Over time, however, I have learned an important lesson: worry should inform us, not consume us.

Our children deserve parents who are vigilant but not fearful. They deserve a childhood filled with joy, not one overshadowed by constant anxiety.

The Societal Challenges That May Come as She Grows

While medical challenges are often visible, social challenges can be equally difficult.

As my daughter grows older, I know she may encounter situations that require resilience and confidence. Some children may ask questions about her scar. Some people may misunderstand her condition. Others may assume she is fragile simply because she has undergone heart surgeries.

My goal is not to shield her from every difficult interaction. My goal is to equip her with confidence.

I want her to be able to say:

“Yes, I have a heart condition. Yes, I have scars. And yes, I can still achieve great things.”

Her scar is not something to hide.

It is evidence of battles fought and won.

Planning for Her Future: Financial Security and Independence

One lesson that CHD parents learn quickly is the importance of planning ahead.

Medical care can be expensive. Lifelong follow-up, medications, investigations, and potential future interventions may carry financial implications.

As parents, one of our responsibilities is to create a strong foundation for our children's future through health-care funds, insurance, emergency savings, investments, and educational opportunities. But financial planning is not only about medical expenses. It is about giving her choices. It is about ensuring she has access to quality education, opportunities, and the freedom to pursue her dreams. The goal is not simply financial security. It is financial independence.

I want her to grow into an adult who can make decisions confidently, support herself if needed, and live a life driven by ambition rather than limitations.

Raising an Independent and Self-Sufficient Child

As parents of children with medical conditions, it is easy to become overprotective. I know because I struggle with it every day. But independence is one of the greatest gifts we can give our children.

As she grows, I want my daughter to understand her own health, take ownership of her medical journey, and develop life skills that help her thrive. After watching your child undergo surgeries and hospitalizations, every instinct tells you to protect them from every possible difficulty. But independence is one of the greatest gifts we can give our children.

As she grows, I want my daughter to understand her own health.

I want her to know:

The name of her heart condition.

The surgeries she has undergone.

The importance of follow-up appointments.

The medications she may need.

When to seek medical help.

I want her to gradually take ownership of her health journey.

Beyond medical knowledge, I want her to learn life skills, problem-solving, responsibility, and resilience. One day, I will not be the one speaking to doctors on her behalf.

One day, she will.

My responsibility is to prepare her for that transition.

Letting Her Be a Child

Perhaps the most important lesson I have learned is that my daughter is not her diagnosis.

She is not a hospital file. She is not an echocardiogram report. She is not a surgical history.

She is a little girl who loves to laugh, play, explore, and dream. For a long time, I viewed everything through the lens of her heart condition.

Now I consciously remind myself to see the whole child.

I want her to climb playground equipment if it is medically safe.

I want her to make friends.

I want her to attend birthday parties.

I want her to have adventures.

I want her to make mistakes and learn from them.

Most importantly, I want her to experience a childhood that feels normal.

Because despite her medical journey, she deserves exactly that.

Building Confidence in Her Own Skin

As parents, our words become our children's inner voice.

If I constantly treat her as fragile, she may grow up believing she is fragile. If I constantly focus on limitations, she may grow up believing she is limited.

Instead, I want her inner voice to say: I am strong. I am capable. I am enough. I can face challenges. I am proud of who I am. Confidence does not come from pretending difficulties do not exist. Confidence comes from knowing that difficulties exist and believing you can overcome them. Her scars do not define her. Her diagnosis does not define her.

Her scars do not define her. Her diagnosis does not define her. Her strength, kindness, determination, and character will define her.

A Letter to My Daughter

My sweet girl, you were never a burden. You were never defined by your condition. You are a fighter, a survivor, and above all, a beautiful human being. Your heart may have needed surgeons to repair it, but it has always been complete in the ways that matter most. Because when I look at you, I do not see a child with congenital heart disease. I see a heart warrior. I see the brave girl who can achieve anything. Don't limit yourself with hurdles that are to come. You are strong enough to make it or break it!

-Your Mommy & Daddy



Rudranshi & family with her Surgeon

Families that stood together



In frame

V.R. Soni & family, Prakash and Meenu Sharma, Aarna & her Mother Anushaa, Siddhant & family

Socio-Intellectual Development in Children with Congenital Heart Disease: An Indian Perspective

By **Amod Kumar Kushwaha** | Assistant Professor & CHD Father



Amod Kushwaha

Congenital Heart Disease (CHD) is one of the most prevalent birth defects globally and poses significant challenges not only to physical health but also to the socio-intellectual development of affected children. While global research has documented cognitive and social vulnerabilities in this population, recent Indian studies provide crucial insights into how these challenges manifest in low- and middle-income contexts. Factors such as delayed diagnosis, limited healthcare access, socioeconomic disparities, and educational constraints make the Indian perspective especially important.

Cognitive and Intellectual Development: Evidence from India

Indian research strongly supports global findings that children with CHD are at risk for cognitive and developmental delays. A large multicentric cohort study conducted across five paediatric cardiac centres in India followed over 1300 infants after cardiac surgery. The study found that **approximately 25.7% of children exhibited motor developmental delay and 15.4% showed mental developmental delay within six months post-surgery.**

These findings highlight that even after successful medical intervention, developmental challenges persist. The mean developmental quotients reported in this study were lower than normative averages, indicating subtle deficits in cognitive functioning.

Similarly, a 2026 Indian narrative review analysing studies from 2000–2025 reported that **14–33% of children showed early motor delays and 15–24% exhibited cognitive delays.** These figures align with international data but also emphasize the variability due to contextual factors such as healthcare access and follow-up systems in Indian scenario.

Another Indian hospital-based study using the Denver Developmental Screening Test (DDST-2) found impairments across multiple domains, including language, personal-social skills, and fine motor abilities, indicating that CHD affects not only intelligence but overall developmental functioning.

Socio-Emotional and Behavioural Development in Indian Context

Indian studies have also highlighted behavioural and social adjustment issues in children with CHD. Research involving ***children aged 4–8 years found a higher prevalence of behavioural problems, impulsivity, and impaired social interaction*** compared to their healthy peers.

These socio-emotional difficulties are often linked to following factors:

- Chronic illness stress
- Repeated hospitalizations
- Overprotective parenting
- Reduced peer interaction

In the Indian context, social stigma and lack of awareness about CHD can further isolate children. Many families, particularly in rural areas, may restrict children's physical and social activities due to fear, unintentionally limiting opportunities for social learning and peer bonding.

Role of Socioeconomic and Environmental Factors

In the Indian context, research have been made to find out the socioeconomic determinants of development in children with CHD. Studies have identified several contextual risk factors:

- Low socioeconomic status
- Limited access to specialized cardiac care
- Delayed surgical intervention
- Malnutrition and poor early stimulation

The 2026 Indian review published in journal *Science Direct* has identified socioeconomic disadvantage and prolonged postoperative illness as major predictors of poor developmental outcomes.

In India, disparities in healthcare infrastructure mean that many children do not receive timely intervention. This delay can lead to prolonged hypoxia and nutritional deficits, both of which negatively impact brain development.

Additionally, broader Indian developmental research (e.g., cohort studies from Mysuru, Pune, and Vellore) emphasizes how early-life nutrition, caregiving environment, and maternal health significantly influence cognitive development. These factors are particularly relevant for children with CHD, who are already biologically vulnerable.

Educational Implications in the Indian Scenario

Educational challenges for children with CHD are compounded in India due to systemic constraints. Cognitive delays, attention deficits, and executive functioning difficulties can hinder academic performance. However, lack of awareness among teachers and absence of structured support systems often mean these children remain undiagnosed or unsupported in classrooms.

Indian studies suggest that:

- Many children with CHD attend regular schools without accommodations.
- Learning difficulties are often misinterpreted as lack of effort.
- Special education services are limited, especially in rural areas.
- Frequent absenteeism due to medical appointments further disrupts academic continuity, leading to learning gaps and reduced self-confidence.
- Developmental Trajectories and Long-Term Outcomes.

Indian longitudinal data remain limited, but available evidence suggests that developmental challenges may persist or even intensify with age. Early deficits in motor and cognitive domains can translate into later difficulties in:

- Academic achievement
- Social relationships
- Emotional regulation

Importantly, the Indian multicentric cohort studies underscore the need for long-term follow-up, as most current data are restricted to early infancy outcomes only.

Intervention and Policy Implications in India

Indian research clearly indicates that improving socio-intellectual outcomes requires system-level interventions, not just medical treatment. Key recommendations include:

1. Early Developmental Screening

Routine neurodevelopmental assessment should be integrated into paediatric cardiac care. Tools like DAS-II and DDST-2 have already been used effectively in Indian settings.

2. Multidisciplinary Care Models

Collaboration among cardiologists, psychologists, educators, and social workers is essential to address the holistic needs of the child.

3. Parental Awareness and Training

Educating parents about developmental milestones and stimulation techniques can significantly improve outcomes, especially in low-resource settings.

4. School-Based Support

Schools should be sensitized to the needs of children with CHD, including:

- Flexible attendance policies.
- Remedial education.

- Psychological counselling.

5. Policy-Level Interventions

Government programs such as early childhood care and education (ECCE) and inclusive education policies need to explicitly include children with chronic medical conditions like CHD.

Strengthening early Interventions, improving awareness and ensuring equitable access to services can significantly enhance the life outcomes.

Conclusion

Indian-context studies enrich our understanding of socio-intellectual development in children with CHD by highlighting the interaction between biological vulnerability and environmental adversity. While cognitive and social challenges are consistent with global findings, the Indian scenario introduces additional layers of complexity due to socioeconomic inequalities, healthcare access issues, and educational limitations.

The evidence clearly shows that a purely medical approach is insufficient. Instead, a holistic, context-sensitive developmental framework is required—one that integrates healthcare, education, family support, and public policy. Strengthening early intervention systems, improving awareness, and ensuring equitable access to services can significantly enhance the life outcomes of children with CHD in India.



PERSPECTIVE OF A MOTHER OF A CHILD WITH SINGLE VENTRICLE PHYSIOLOGY

By **Dr. Jonali Choudhury (Ph.D)** | Assistant Professor and CHD Mother, Guwahati



Dr. Jonali Choudhury

As a mother of a child with a complex congenital heart defect (CHD), particularly a single ventricle condition, I would like to share some of the challenges that parents face throughout their journey.

THE DIAGNOSIS

After the diagnosis of any CHD, parents are suddenly thrown into financial, social, and emotional difficulties. The situation becomes even more overwhelming when the child has a complex CHD such as a single ventricle defect. At that stage, parents face enormous confusion and uncertainty.

One of the biggest challenges is the difference in the opinions among experts.

DIFFERENCES IN OPINIONS

One of the biggest challenges is the difference in opinions among experts. These differences are not only seen between hospitals and institutions but sometimes even within the same institution. Personally, I received different opinions regarding the timing of Fontan surgery. There were also differing views on whether a Blalock-Taussig (BT) shunt should be performed when Fontan surgery was not considered feasible. Such conflicting advice leaves parents uncertain and anxious, especially when they are expected to make critical decisions regarding their child's future.

It would be immensely helpful if experts could come to some common conclusions and develop standard guidelines for parents. Such guidance would reduce confusion and help families make informed decisions.

CHOOSING THE RIGHT HOSPITAL

Another major challenge is selecting the best hospital for a child with CHD.

Parents often ask: Which hospital is best for my child's condition? Is there any reliable data available? We need transparent and unbiased information regarding hospitals, their expertise, and outcomes for various cardiac procedures. A standardized and trustworthy ranking or reporting system would help families make better-informed decisions.

However, such comparisons must be designed carefully because different centers treat different types of patients with varying levels of risk. Outcome comparisons should therefore account for these differences to avoid misleading conclusions.

FINANCIAL CHALLENGES

For many middle-class families, treatment costs are enormous. And for single ventricle children's multiple surgeries are needed in a staged way. And to decide on the next surgery. Multiple diagnostic procedures and imaging are necessary in between two major surgeries. Although some government schemes, such as those under RBSK and other state-supported programs, aid in states like Assam, West Bengal, Kerala, and Gujarat, access often depends on various eligibility criteria such as age limits, family income, and other conditions.

In addition, there are only a limited number of specialized CHD centers in many regions. This creates constant anxiety. We are always worried about what we would do if an emergency arose and specialized care are not immediately available.

For a middle-class family, treatment costs are enormous. Even more financially when there are multiple surgeries.

DECISION MAKING

We are often required to make life-changing decisions on behalf of our children. Deciding whether to proceed with surgery can be one of the most difficult responsibilities a parent faces. Doctors generally explain that surgery can help, but often they cannot provide certainty about the extent of improvement or long-term outcomes. Parents are left trying to balance hope, risk, and uncertainty. Personally, I am lucky to be in the care of a team like a family that suggested clearly what was best for my kid. That was empowering in making the decision.

This mental struggle can be exhausting. Every family wants the best for their child, yet the information available is often incomplete, making decisions even more stressful.

SOCIAL AND EMOTIONAL CHALLENGES

Beyond the medical and financial difficulties, families also face social challenges. Parents must learn to accept the limitations that their child may have. Activities that other families take for granted—travelling, attending events, participating in physical

Activities often require careful planning and consideration.

There is also a constant fear of judgment. Mothers may feel scrutiny and blamed whenever something goes wrong. Even educated individuals may criticize parenting decisions without fully understanding the realities of living with CHD.

Many parents also experience emotional distress when their child's growth, development, or prospects are compared with those of healthy children. Such comparisons can be deeply hurtful and add to the burden families already carry.

There is a constant fear of social judgement.

WHAT WE NEED

We, the parents of children with complex CHD like single ventricle physiology, need clear, evidence-based guidance, transparent information about treatment centers, better access to financial support, and greater awareness within society.

Most importantly, CHD families need empathy. Behind every child with CHD is a family navigating uncertainty, making difficult decisions, managing financial pressures, and carrying emotional burdens that are often invisible to others.



Dr. Jonali Choudhury & Ribrib

Congenital Heart Disease in India: Towards Legal Recognition, Social Inclusion and Constitutional Protection

By **Ankita Shah** | Advocate and CHD Sister, Pune



Adv Ankita Shah

This topic is not merely an academic exercise for me; it is a reality that my family has lived with for years. My elder brother has been suffering from Congenital Heart Disease (CHD), and through his journey, I have witnessed the immense physical, emotional, psychological and financial burdens that accompany this condition. The struggle does not end with diagnosis or surgery. It continues throughout life in the form of regular medical consultations, uncertainty regarding health, limitations in daily activities, social challenges and concerns about education and employment.

What makes the plight of CHD patients particularly difficult is that it is often an invisible disability. Unlike many physical disabilities that are visibly apparent, CHD may not be noticed by society. A person may appear healthy from the outside while silently enduring fatigue, breathlessness, repeated hospital visits, lifelong medication and constant medical supervision. The absence of visible symptoms often results in a lack of understanding, empathy and institutional support. Consequently, many individuals suffering from CHD find themselves excluded from benefits and protections despite facing substantial limitations in their daily lives.

The Constitution of India embodies the ideals of justice, equality, dignity and compassion. Article 21 guarantees the Right to Life and Personal Liberty. The Supreme Court has consistently interpreted this provision in a broad and progressive manner. In *Maneka Gandhi v. Union of India*, the Court transformed the understanding of fundamental rights by holding that constitutional guarantees must receive a liberal and purposive interpretation. Thereafter, through a series of judicial pronouncements, the Court expanded the scope of Article 21 to include the right to health, medical care, human dignity, education and the conditions necessary for leading a meaningful and dignified life. The constitutional promise of life is therefore not confined to mere animal existence but extends to the opportunity to live with dignity, security and equal participation in society.

The challenges posed by Congenital Heart Disease must be viewed through this constitutional lens. According to medical estimates, approximately 240,000 children are born with CHD in India every year, and nearly 50,000 of them require medical or surgical intervention within the first year of life.

Yet countless children fail to receive timely diagnosis and treatment because of financial hardship, lack of awareness and inadequate access to specialised healthcare facilities. These figures demonstrate that CHD is not merely a medical condition but a significant social, economic and legal concern that demands policy attention.

The legal position at present is that heart ailments are not specifically recognised as disabilities under the Rights of Persons with Disabilities Act, 2016. In *Union of India v. Ex. LNK Baljit Singh* (2021), the Supreme Court observed that heart disease does not presently fall within the statutory definition of disability under the Act. However, the judgment merely interpreted the law as enacted by Parliament; it did not rule that persons suffering from severe cardiac conditions are undeserving of protection. The authority to expand the scope of the legislation and respond to evolving social realities remains with the Legislature.

Disability jurisprudence across the world has increasingly moved beyond the traditional understanding of disability as a visible physical impairment. Modern approaches recognise that chronic illnesses, invisible disabilities and long-term medical conditions may substantially restrict an individual's ability to participate fully and effectively in society. In this context, the experiences of persons living with Congenital Heart Disease deserve serious consideration from lawmakers, policymakers and society at large.

Additional Measures Required for Persons with CHD

Even if Congenital Heart Disease is not immediately included within the ambit of the Rights of Persons with Disabilities Act, 2016, the State has a constitutional obligation under Articles 21, 38, 39, 41 and 47 to formulate welfare measures that protect the health and dignity of affected individuals.

The following measures deserve urgent consideration:

1. Travel Concessions

Individuals suffering from CHD frequently travel long distances for specialised consultations, surgeries and follow-up treatment. Travel often becomes a recurring financial burden for families already struggling with medical expenses. Therefore, concessions in railway, road and air travel should be extended to CHD patients and, where necessary, their caregivers.

2. Educational Support

Children suffering from CHD may experience prolonged absences from school due to hospitalisation, surgeries and recovery periods. Educational institutions should adopt inclusive policies such as attendance relaxation, flexible learning mechanisms, examination accommodations and scholarship support to ensure that no child is deprived of education because of a medical condition beyond their control.

3. Healthcare and Surgical Assistance

Access to healthcare should not depend upon a family's financial capacity. The Government should strengthen public healthcare schemes to provide free or subsidised diagnostic services, medicines, surgeries and long-term follow-up care. Specialised cardiac centres should be established in underserved regions to ensure equitable access to treatment.

4. Mental Health and Counselling Services

The burden of CHD extends beyond the physical body. Patients and their families often experience anxiety, depression, emotional distress and uncertainty regarding the future. Professional counselling, psychological support and rehabilitation services should therefore form an integral component of CHD care.

5. Awareness and Guidance Mechanisms

A significant number of families remain unaware of available treatment options, government schemes and long-term management strategies. Dedicated support and guidance centres should be established to provide accurate information and assistance regarding healthcare, education, employment opportunities and welfare benefits.

6. Employment Protection

Many adults living with CHD face discrimination in recruitment and employment despite being capable of performing their duties effectively. Appropriate safeguards should be introduced to prevent unfair discrimination and to encourage employers to provide reasonable accommodations wherever required.

7. Recognition of Invisible Disabilities

The law must evolve with changing social realities. Disability is not always visible. Many conditions, including severe forms of Congenital Heart Disease, may not alter a person's outward appearance but can significantly restrict physical functioning and participation in social and economic life. Future legislative reforms should therefore consider adopting a more inclusive understanding of disability that recognises invisible and chronic medical conditions within an appropriate legal framework.

CHD has been a reality to me and not just another academic topic with my brother being through the journey all his life.

Conclusion

The true strength of a constitutional democracy is measured by the way it treats its most vulnerable citizens. The principles of equality, dignity and social justice embodied in Articles 14, 21 and 41 of the Constitution require the State to extend protection and support to those who face disadvantages through no fault of their own.

For families living with Congenital Heart Disease, the struggle is not confined to hospital walls. It is reflected in missed educational opportunities, financial hardship, emotional distress, social misunderstanding and uncertainty about the future. Behind every medical statistic is a child fighting for survival, a parent searching for treatment and a family striving to maintain hope.

While the Supreme Court has clarified that CHD is presently outside the scope of the Rights of Persons with Disabilities Act, 2016, the issue remains open for legislative reform. The law must not remain static when social realities demand change. It is therefore imperative for Parliament and policymakers to reconsider the position of persons suffering from severe Congenital Heart Disease and to provide

them with appropriate legal recognition, healthcare support, educational assistance, employment safeguards and social security measures.

A compassionate and inclusive society does not wait for suffering to become visible before it offers support. The constitutional promise of dignity and equal opportunity must extend to those whose disabilities may be unseen, but whose struggles are real. Only then can the ideals of justice and humanity enshrined in the Constitution be truly fulfilled.



Ankita & her brother Nikhil

Careers of CHD Warriors: Beyond the Diagnosis, Building Dreams

By **Dr. Rakesh Bhowmick (Ph.D)** | Senior Scientist and CHD Father, Kolkata



Dr. Rakesh Bhowmick

Careers of CHD Warriors: Beyond the Diagnosis, Building Dreams

A diagnosis of congenital heart disease (CHD) often begins a journey filled with uncertainty, hospital visits, surgeries, medications, and countless moments of fear and hope. For many parents, the first question after hearing “your child has a heart defect” is not only “Will my child survive?” but also “Will my child have a normal future?”

A future that includes education, friendships, independence, dreams, and a meaningful career.

Today, thousands of CHD warriors are proving that their hearts may have needed medical care, but their dreams are just as strong as anyone else’s.

From Hospital Beds to Classrooms

The childhood of a CHD warrior can look different. Frequent hospital visits, recovery periods, restrictions, and medical appointments may interrupt school life. Some children miss classes or struggle to keep up academically because their energy is focused on healing.

But many CHD warriors develop incredible strength, patience, and resilience from a young age. The same qualities that help them overcome surgeries often become their greatest strengths later in life — determination, discipline, empathy, and the ability to face challenges.

With proper medical follow-up, emotional support, and encouragement, many CHD warriors successfully pursue higher education and professional careers.

Choosing Careers: Breaking the Myths

For years, there has been a misconception that CHD survivors cannot achieve demanding careers. While some individuals may have limitations depending on their heart condition, surgeries, and medical status, many can pursue a wide variety of professions.

CHD warriors have become:

- Doctors and healthcare professionals who bring personal understanding to patient care
- Engineers and scientists who solve complex problems
- Teachers who inspire future generations
- Artists, writers, and creators who share powerful stories
- Entrepreneurs who build their own paths

- Researchers working toward better healthcare
- Advocates creating awareness for congenital heart disease

Their achievements remind the world that a medical diagnosis does not define a person's potential.

Challenges They May Face

The journey is not always easy. Some CHD warriors may face challenges such as:

- Concerns about physical stamina or limitations
- Anxiety about their health while planning careers
- Fear of discrimination during education or employment
- Questions about whether they can handle workplace responsibilities
- The need for regular medical follow-up throughout life

These challenges require understanding from families, schools, workplaces, and society.

A CHD warrior should be evaluated for their abilities, skills, and passion — not only by their medical history.

The Role of Parents and Society

Parents of CHD warriors often become their strongest support system. Encouraging independence, confidence, and self-belief is just as important as medical care.

Instead of raising children with the mindset of “you cannot,” CHD warriors need the message:

“You may have faced more battles than others, but those battles have made you stronger.”

Schools and workplaces also play an important role by creating inclusive environments where individuals are supported based on their needs and abilities.

CHD in School: Challenges Children May Face

Children with congenital heart disease (CHD) often appear healthy, but many face challenges that are not immediately visible.

- Frequent hospital visits, surgeries, and medical appointments can lead to missed classes and learning gaps.
- Fatigue, reduced stamina, or breathlessness may make it difficult to participate in sports, physical education, or long school days.
- Some children experience neurodevelopmental or learning difficulties, including problems with attention, memory, processing speed, executive function, or fine motor skills.
- Long absences may affect friendships, confidence, and social inclusion.
- Anxiety about medical procedures or feeling “different” can impact emotional well-being.
- Bullying, overprotection by adults, or low expectations from others may limit a child's confidence and independence.

With understanding teachers, reasonable accommodations, and family support, most children with CHD can thrive academically and socially.

CHD in Adulthood: Career and Workplace Challenges

Thanks to advances in medical care, most children born with CHD now survive into adulthood. However, adulthood brings its own set of challenges.

- Some adults experience reduced exercise tolerance, fatigue, arrhythmias, heart failure, or require repeat surgeries or pacemaker follow-ups, which may affect work capacity.

- Regular medical appointments and occasional hospitalizations can interfere with work schedules.
- Certain physically demanding occupations or jobs involving extreme environments may not be medically advisable for some individuals.
- Difficulties obtaining life insurance, health insurance, or certain employment clearances may create additional barriers in some countries.
- Some adults face discrimination or misconceptions from employers who assume they are less capable despite being fully qualified.
- Living with a lifelong heart condition can contribute to anxiety, depression, or uncertainty about career progression and financial security.
- Family planning, pregnancy considerations, and balancing health with professional responsibilities may require careful planning.

Despite these challenges, many adults with CHD build successful careers as doctors, engineers, scientists, teachers, entrepreneurs, artists, athletes, and leaders. Their diagnosis does not define their potential. With appropriate medical care, workplace flexibility, and supportive employers, they can achieve fulfilling professional and personal lives.

A New Definition of Strength

A CHD warrior's success is not measured only by awards, degrees, or job titles. Success is waking up every day with courage, pursuing dreams, and refusing to let a repaired heart limit an unbreakable spirit.

Every CHD warrior carries a story — a story of survival, courage, and hope.

Their scars are not signs of weakness. They are reminders of battles won.

The future of CHD warriors is not just about surviving childhood.

It is about thriving, creating, leading, and inspiring.

Because behind every repaired heart is a powerful dream waiting to beat.

Living with CHD: Challenges Beyond the Workplace

While many CHD warriors go on to lead successful and fulfilling lives, congenital heart disease remains a lifelong journey for many. The challenges extend beyond choosing a career and can influence various aspects of daily living.

The nature and severity of these challenges vary widely depending on the type of heart defect, previous surgeries, residual heart problems, and overall health. Many individuals experience few limitations, while others require ongoing medical care and lifestyle adjustments.

Some of the common challenges include:

- **Lifelong medical follow-up:** Most CHD survivors require regular evaluations by a cardiologist, periodic investigations such as echocardiography or electrocardiography, and, in some cases, additional interventions or surgeries later in life.
- **Reduced exercise tolerance:** Some individuals may tire more easily or have limitations in strenuous physical activities, although many can safely participate in regular exercise under medical guidance.
- **Cardiac rhythm disorders:** Arrhythmias may develop years after corrective surgery, occasionally requiring medications, catheter-based procedures, or pacemaker or implantable defibrillator therapy.
- **Neurodevelopmental and learning difficulties:** Certain children, particularly those who underwent complex heart surgery during infancy, may experience challenges with attention, executive functioning, memory, speech, or learning. Early intervention and educational support can significantly improve outcomes.
- **Emotional and mental health:** Living with a chronic heart condition can contribute to anxiety, depression, fear of future medical procedures, body image concerns related to

surgical scars, or uncertainty about the future. Psychological support should be considered an integral part of comprehensive CHD care.

- **Social participation:** Some children may feel different from their peers because of activity restrictions, repeated hospitalizations, or visible surgical scars. Building self-confidence and fostering inclusion are essential for healthy emotional development.
- **Transition to adult healthcare:** As adolescents become adults, moving from paediatric to adult congenital heart disease (ACHD) care can be challenging. Continued follow-up with specialists is crucial to maintaining long-term health.
- **Family planning and pregnancy:** For many women with CHD, pregnancy is possible but requires careful planning and multidisciplinary medical supervision. Genetic counselling and pre-pregnancy cardiac evaluation may also be recommended in selected cases.
- **Employment and insurance:** Some adults may encounter difficulties related to physically demanding occupations, health insurance, or misconceptions about their abilities despite being fully capable of performing many professional roles.

Importantly, these challenges should not overshadow the tremendous progress achieved in congenital heart disease care. Today, most children born with CHD survive into adulthood, and many pursue higher education, establish successful careers, build families, and contribute meaningfully to society.

Every CHD warrior's journey is unique. While some may face significant medical hurdles, others live with minimal limitations. The key is individualized care, informed decision-making, and a strong support system that empowers everyone to reach their fullest potential.

Real life stories made-

CHD Warriors at the Olympics: When a Repaired Heart Reaches the Podium

1. Roger Black MBE: From Congenital Heart Disease to Olympic Silver Medal

British Olympic athlete Roger Black is one of the most inspiring examples of a CHD warrior in elite sport. He was diagnosed in childhood with a congenital heart condition involving his aortic valve. As a young athlete, he faced uncertainty about whether he would be able to participate in competitive sports. With careful monitoring and medical guidance, he continued his journey and became one of Britain's greatest 400-metre runners. Roger Black represented Great Britain at the Olympics and won a silver medal in the 400 metres at the 1996 Atlanta Olympics. His journey showed that a congenital heart diagnosis does not automatically end an athlete's dream.

2. Shaun White: Five-Time Olympian and Tetralogy of Fallot Survivor

Shaun White, one of the most recognized snowboarders in the world, was born with Tetralogy of Fallot with pulmonary atresia, a complex congenital heart condition. He underwent multiple heart surgeries as a child. Despite this early challenge, he went on to become a five-time Olympian and Olympic gold medallist in snowboarding. His journey has inspired thousands of CHD families because it challenges the idea that children born with heart defects must always live limited lives.

Real life heart heroes at international space:

1. Hunter Appleton was born with coarctation of the aorta and faced serious challenges during childhood, including complications after surgery. Instead of allowing his medical history to define his future, he chose to study medicine and pursue the dream of becoming a paediatric cardiothoracic surgeon — someone who could one day help children like himself.
2. Bret Michaels — Lead vocalist of the band Poison. Born with Tetralogy of Fallot, he underwent corrective surgery as a child and later achieved international success in music and television.
3. Molly Hemphill, a congenital heart disease survivor, became a competitor on the television show American Ninja Warrior, showing extraordinary physical strength and determination despite her heart journey.
4. Chris O'Connell, another CHD survivor, also competed on American Ninja Warrior, proving that a CHD diagnosis does not automatically define physical capability.

5. Chris Kidwell, born with d-transposition of the great arteries, grew into adulthood as a CHD survivor and shares his journey to inspire others living with congenital heart disease.
6. Cristina Civetta was born with pulmonary atresia and a hypoplastic right ventricle and underwent multiple procedures throughout life. Today, she has built a professional career as a real estate broker and event producer while embracing her identity as a CHD survivor.
7. Talia Joy Castellano – Beauty influencer and motivational figure. She was born with a congenital heart defect in addition to battling cancer and inspired millions through her positivity.
8. Tony Award-winning actor Corbin Bleu – Frequently participates in CHD awareness campaigns because of family involvement, helping raise public awareness.
9. Jimmy Kimmel – While he does not have CHD himself, he has become one of the most prominent advocates for CHD awareness after his son was born with a complex congenital heart defect.
10. Erin Hunter-McPhan, born with Tetralogy of Fallot and after multiple surgeries, went on to work in healthcare, including at the hospital connected with her own childhood treatment journey.
Her career became a bridge between being a patient and becoming a caregiver.

Real life heart heroes at Indian space:

1. Madhubala is one of the most well-known historical figures associated with Congenital Heart Disease. She was born with a **ventricular septal defect (VSD)**, a congenital heart defect in which there is a hole in the wall separating the two lower chambers (ventricles) of the heart. Despite living with congenital heart disease (CHD), Madhubala rose to become one of the greatest and most beloved actresses in Indian cinema. Renowned for her extraordinary beauty, grace, and remarkable performances in classics such as *Mughal-e-Azam*, she captivated audiences across generations. Her life stands as a powerful reminder that courage, talent, and determination can leave an enduring legacy despite serious health challenges.
2. Indian cricketer Yash Dhull, who was diagnosed with a congenital heart defect involving a hole in the heart and underwent treatment, returned to competitive cricket after recovery and rehabilitation. His comeback highlighted the importance of medical care, patience, and determination in allowing CHD survivors to pursue their passions.
3. In Coimbatore, India, a teenager diagnosed with Ebstein anomaly, a congenital heart condition, underwent surgery and was able to return to school, dancing, and normal activities. Her story reflects the hope that timely diagnosis, expert care, and family support can bring to children with CHD.

The Role of Parents: Raising a Future Adult, Not Just a Patient

For CHD parents, medical care is only one part of the journey.

A child with CHD needs:

- Protection, but also independence
- Medical guidance, but also confidence
- Awareness of limitations, but also encouragement to explore possibilities

The goal is not only to help a child survive surgery. The goal is to help that child discover who they can become.



News Highlights

The Times of India | 26 Jun 2026

GRH performs complex cardiac stent procedure

Government Rajaji Hospital, Madurai successfully treated a 17-year-old girl with a rare congenital heart defect (Sinus Venosus ASD) using a transcatheter covered stent, avoiding open-heart surgery.



Government Rajaji Hospital (GRH) in Madurai has achieved a medical landmark by performing Tamil Nadu's first successful transcatheter...

Madurai: The cardiology department at Government Rajaji Hospital (GRH) in Madurai has successfully performed a transcatheter covered stent implantation to treat congenital heart disease. The procedure was carried out on a 17-year-old girl from Virudhunagar district, who had features suggestive of Sinus Venosus Defect (Superior Vena Cava Type Atrial Septal Defect).

The hospital said this was the first time the procedure was successfully performed in a govt medical college hospital in [Tamil Nadu](#). "Traditionally, patients with SVC Type Sinus Venosus ASD are treated by open-heart

surgery. The novel transcatheter technique involved deployment of a specially designed covered stent within Superior Vena Cava (SVC) to close the defect and exclude the interatrial communication by redirecting blood flow," said Dr G Selvarani, professor and head, department of cardiology, who led the procedure. A team of cardiologists with the help of a team of anesthetists with the backup of cardio thoracic vascular surgery team performed the procedure. Dr Pramod Sagar from Chennai, an internationally recognised expert in structural heart interventions, guided the team.

The consumables and sophisticated hardware cost around Rs5 lakh, but the procedure was carried out under CMCHIS scheme free of cost for the patient.

Source link: <https://timesofindia.indiatimes.com/city/madurai/grh-performs-complex-cardiac-stent-procedure/articleshow/132022620.cms>

The Times of India | 11 April 2026

Congenital Heart Disease Screening in Ranchi: 101 Children Diagnosed, Free Treatment in Kochi

A screening programme in Ranchi identified 101 children with congenital heart disease. The children were referred for free treatment in Kochi through a charitable healthcare initiative.

Ranchi: The state chapter of National Health Mission (NHM), in collaboration with a Kochi hospital organised a congenital heart disease (CHD) screening camp at Ranchi Sadar Hospital on Friday and Saturday.

As many as 292 children were screened over the two days, with 101 detected with CHD. Those diagnosed with conditions requiring surgical intervention will be referred to the Amrita Hospital in Kochi, where they will receive free treatment.

State nodal officer of Rashtriya Bal Swasthya Karyakram (RBSK), Dr Vijay Kishore Rajak, said that children screened at the camp were identified by doctors at the district level. "The children will undergo a final screening at Ranchi Sadar Hospital. Among the children, those requiring surgeries will be sent to Kochi for treatment. The patients included 43 from Ranchi, 25 from Khunti, 20 from Godda and 27 from Chatra," Rajak said.

He said that a memorandum of understanding (MoU) was signed between the Kochi hospital and NHM in Jan to detect and treat CHD patients in the state. Under the MoU, Jharkhand govt will also bear transportation and lodging expenses, along with medical expenses.

Source link: <https://timesofindia.indiatimes.com/city/ranchi/congenital-heart-disease-screening-in-ranchi-105-children-diagnosed-free-treatment-in-kochi/articleshow/130196495.cms>

The Times of India | 03 April 2026

Minimally invasive procedure corrects rare heart defect in 64-year-old in Madurai

Doctors repaired a rare congenital Sinus Venosus ASD in a 64-year-old patient using a catheter-based technique instead of open-heart surgery.



Madurai: Meenakshi Super Speciality Hospital in Madurai has successfully treated a 64-year-old farmer with a rare congenital heart defect — sinus venosus atrial septal defect (ASD) — using a minimally invasive transcatheter technique, avoiding open-heart surgery.

The patient had presented with worsening breathlessness on exertion, fatigue and palpitations that began affecting his daily activities. Detailed cardiac evaluation, including echocardiography and a

CT scan, revealed the previously undiagnosed condition.

Sinus venosus ASD is a rare defect characterised by an abnormal opening between the heart's upper chambers, leading to improper blood flow. In this case, it caused a left-to-right shunt, resulting in enlargement and increased workload of the right side of the heart.

Doctors treated the defect using a transcatheter-covered stent procedure, in which a specially designed stent was delivered through a blood vessel to seal the opening and restore normal circulation. The approach eliminated the need for open-heart surgery.

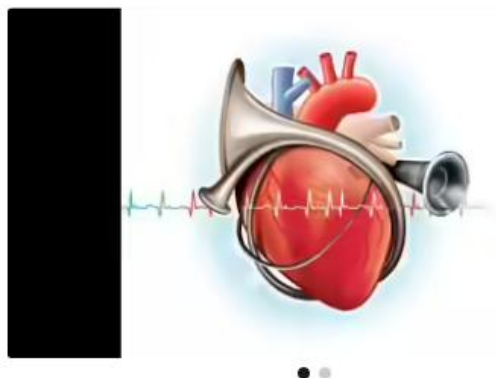
The procedure was performed by Dr R Sivakumar, senior consultant and head of cardiology, along with Dr S Kumar and the catheterisation lab team. The patient was monitored in the ICU for 24 hours and later discharged in stable condition.

Source link: <https://timesofindia.indiatimes.com/city/madurai/minimally-invasive-procedure-corrects-rare-heart-defect-in-64-year-old-in-madurai/articleshow/129988416.cms>

The Times of India | 26 Jan 2026

Registry of congenital heart diseases for early detection

The Rajasthan government announced a Child Heart Disease Registry, regional CHD hub, expanded 2D Echo screening, and improved referral systems under RBSK to improve early diagnosis and treatment.



Jaipur: To spot congenital heart diseases (CHD) early, manage them, treat them, and keep up regular follow-ups, the health dept will set up a child heart disease registry, build up a regional CHD hub, and roll out expanded 2D Echo services.

The dept aims to ensure effective statewide CHD care by building up technical capacity and tightening up referral-to-treatment pathways. "The department is planning system upgrades that include setting up a

child heart disease registry to track cases and outcomes, building up a regional CHD hub to line up specialist services, and rolling out expanded 2D Echo services to step up screening and diagnosis. The dept will also work with stakeholders so children from rural areas can get to timely treatment at major centres," a senior health dept official said.

Under the Centre's Rashtriya Bal Swasthya Karyakram (RBSK), the state has scaled up CHD care for children through medicines and surgeries, and by setting up a new Rs 20-crore CTVS surgery unit at JK Lon Hospital in 2025. Similar cardiac facilities are set to come up at other state hospitals.

JK Lon Hospital's CTVS unit is taking in cases of atrial septal defect (ASD), one of the most common heart defects in children that calls for surgical treatment.

In ASD, a child's heart has an abnormal opening in the septum that separates the upper chambers (atria).

Children with infections that wear down heart valves and then need surgery have also been reported. Several congenital conditions affecting the heart's arteries that also call for surgery in children have been logged at the centre.

The health department is stepping up efforts to pick out children with CHD so they can get treated on time. A senior health department official said, "Under the Centre's RBSK, treatment for heart diseases and other conditions in newborns and children has been steadily built up through various state government schemes. This has helped save the lives of many children with complex conditions."

Source link: <https://timesofindia.indiatimes.com/city/jaipur/registry-of-congenital-heart-diseases-for-early-detection/articleshow/127498956.cms>

The Times of India | 22 May 2026
28 kids sent to Ahmedabad for free heart cure

Bihar government facilitated free treatment for 28 children with serious heart conditions, many involving congenital heart disease, at a specialist hospital in Ahmedabad.

Patna: State health minister [Nishant Kumar](#) on Friday said 28 children suffering from congenital heart disease were sent to Shri Satya Sai Heart Hospital in Ahmedabad for free treatment under the 99th batch of the state-run Baal Hriday Yojana.

He, through a press release, said the scheme has so far enabled the successful treatment of 3,028 children across Bihar, calling it a life-giving initiative for poor and needy families struggling with the burden of costly cardiac care.

Nishant said the Baal Hriday Yojana was launched on April 4, 2021, by then CM Nitish Kumar under Saat Nishchay-2 with the aim of strengthening "additional health facilities for all." The scheme provides free treatment and medical care to children aged 0 to 18 years who are born with congenital heart defects, especially cases involving a hole in the heart.

He said the latest batch includes children from Araria, Arwal, Aurangabad, Darbhanga, East Champaran, Kishanganj, Lakhisarai, Muzaffarpur, Patna, Saran, Sheohar, Supaul, Saharsa and Kaimur districts. All of them will receive free surgery and treatment under the supervision of specialist doctors at the Ahmedabad hospital.

Nishant said the health department regularly conducts health camps and screening programmes in districts across the state to identify children suffering from congenital heart disease. After detailed examination by specialist doctors, affected children are referred for treatment to leading institutions including IGIC, IGIMS, Medanta Hospital in Patna and Shri Satya Sai Heart Hospital in Ahmedabad, depending on medical requirements.

He wished the children a speedy recovery and said the state govt remains focused on making quality healthcare accessible to every needy citizen. He said Baal Hriday Yojana stands as an example of commitment, bringing renewed hope to thousands of children and their families across Bihar.

Source link: <https://timesofindia.indiatimes.com/city/patna/28-kids-sent-to-ahmedabad-for-free-heart-cure-minister/articleshow/131264396.cms>

Disclaimer

Hriday Gatha is a biannual magazine dedicated to raising awareness about congenital heart disease (CHD), promoting education, and sharing the experiences of patients, caregivers, healthcare professionals, and researchers.

The information published in this magazine is intended solely for educational and awareness purposes. It should not be considered a substitute for professional medical advice, diagnosis, or treatment. Readers are advised to consult qualified healthcare professionals regarding any medical condition or treatment decisions.

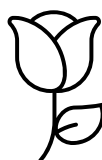
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Together, We Are Stronger

Thank you to every contributor who shared their story with courage and honesty. Every voice in these pages reminds us that no heart warrior walks alone.

HRIDAY GĀTHĀ | Volume II, Issue I

