



HRIDAY GĀTHĀ

Let's

CHALLENGE HEART DEFECTS

Together

Editor: Dr. Suchismita Halder

A Biannual Publication by Justice for Heart Warriors
Volume 1 | Issue 2 | June to December 2025

HRIDAY GĀTHĀ



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Acknowledgements

We sincerely thank all patients, caregivers, and families who continue to inspire the work of the congenital heart disease (CHD) community. Their resilience and lived experiences form the foundation of awareness and advocacy efforts.

We also acknowledge the contributions of clinicians, researchers, and volunteers who have supported the development of this issue of Hriday Gatha. Special appreciation is extended to

- Dr. R. Krishna Kumar, Clinical Professor and Head of the Department of Pediatric Cardiology at Amrita Hospital in Kochi
- Dr. Atul Prabhu, Interventional Pediatric Cardiologist and Electrophysiologist, Narayana Institute of Cardiac Sciences, Narayana Healthcity, Bangalore
- Ms. Veeralakshmi Rajasekhar, Country Director for India at Children's HeartLink

for helping and supporting with this issue of Hriday Gatha.

Funding Statement

No funding was received for the preparation of this issue. All activities were carried out as part of ongoing awareness and advocacy initiatives.

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From the Editor

For many families, the word *surgery* feels like a finish line. Months—sometimes years—of fear, uncertainty, and waiting seem to culminate in a single date on the calendar. And when that day passes successfully, there is relief, gratitude, and hope. Yet for children born with congenital heart disease (CHD), surgery is not an end. It is often only the beginning of a lifelong journey.

CHD care unfolds quietly over the years. It follows children into classrooms where fatigue is invisible, into playgrounds where limits must be negotiated, and into adolescence where questions of identity, independence, and uncertainty grow louder. It continues into adulthood, where transition of care becomes a challenge in itself, where pediatric files must translate into adult services, and childhood survivors learn to advocate for their own hearts. For some, this journey may extend further into advanced therapies, transplantation, or complex long-term medical support. For all, it requires continuity, vigilance, and trust.

The CHD story is written not only in operating theatres and catheterization labs, but also in developmental clinics, dental chairs, physiotherapy rooms, mental health spaces, and family dining tables. Pediatricians, nurses, intensivists, psychologists, educators, social workers, and parents become equal partners in care. Mental health, neurodevelopment, schooling, and social inclusion are not peripheral concerns; rather, they are central to survival with dignity.

This issue of *Hriday Gatha* is dedicated to that reality: that CHD care does not end with a successful procedure, but evolves across life stages and specialties. The voices in this edition reflect the complexity of this journey—professionals who have walked alongside families over decades, parents navigating schooling and emotions beyond the hospital gates, and CHD warriors who speak honestly about uncertainty, resilience, and growth.

At its heart, this issue is about the partnership between families and care teams, between medicine and mind, and between survival and quality of life. As we share these stories, reflections, and experiences, we hope to move the conversation beyond “fixing a heart” toward supporting a whole life.

Because living with CHD is not a single event.

It is a lifelong story and it deserves to be told in full.

Suchismita Halder

Understanding Congenital Heart Defects

What are Congenital Heart Defects?

Congenital heart defects (CHDs) are problems with the structure of the heart that are present from birth. These defects occur when the heart does not develop normally during pregnancy. CHDs are the most common type of birth defect, occurring in about 1 in every 100 live births. This means that out of every 100 babies born, at least one may have a congenital heart defect.

CHDs can affect different parts of the heart. Some common types include septal defects (holes in the wall between the left and right sides of the heart), heart valve defects, and abnormalities of the large blood vessels connected to the heart.

CHDs can range from very mild conditions that require little or no treatment to complex defects that require surgery or lifelong care.

What Causes CHDs?

In many cases, the exact cause of congenital heart defects is not known. They occur during early pregnancy when the baby's heart is forming.

Some CHDs are related to genetic or chromosomal conditions, such as Down syndrome. Certain maternal health conditions or environmental factors during pregnancy may also increase the risk. These include infections such as rubella, poorly controlled diabetes, certain medications, alcohol use, or exposure to harmful substances. However, in many children no specific cause can be identified. Most congenital heart defects cannot be prevented, but certain measures during pregnancy may help reduce the risk.

How are CHDs Detected?

Some CHDs can be detected before birth through fetal echocardiography, a specialized ultrasound used to examine the baby's heart during pregnancy.

After birth, a CHD may be suspected during a routine examination if a doctor hears a heart murmur or if the baby shows symptoms such as difficulty breathing, poor feeding, unusual tiredness, or a bluish discoloration of the skin, lips, or fingernails (cyanosis).

To confirm the diagnosis and determine the type of heart defect, doctors may perform tests such as echocardiography (heart ultrasound), electrocardiogram (ECG), chest X-ray, or cardiac catheterization.

Treatment and Care

Treatment for CHDs depends on the type and severity of the defect. Possible treatments include medications, cardiac catheterization procedures, or heart surgery.

Advances in pediatric cardiology and cardiac surgery have greatly improved outcomes for children with CHDs. Many children born with congenital heart defects today grow up to lead active and fulfilling lives.

Lifelong Follow-up

CHDs require lifelong care. Even after successful surgery or treatment, regular follow-up with a pediatric cardiologist or a specialist in adult congenital heart disease is important.

Some individuals may require additional procedures later in life, while others may only need periodic monitoring. Regular medical care helps ensure early detection of complications and better long-term health.

The Situation in India

In India, more than two lakh children are born with congenital heart defects every year. About one-fifth of these children have serious defects that require medical or surgical intervention in the first year of life. Unfortunately, advanced cardiac care is still accessible to only a minority of children who need it.

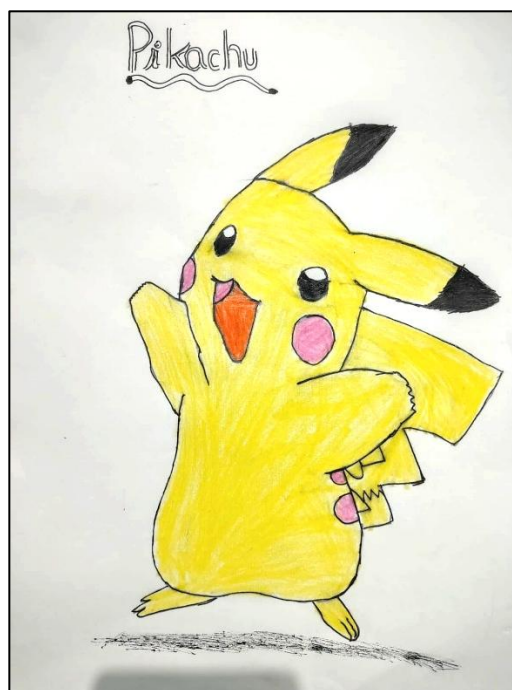
Why Awareness Matters

Increasing awareness about CHDs can help promote early diagnosis and timely referral for specialized care. Expanding training opportunities for pediatric cardiologists, pediatric cardiac surgeons, and pediatric anesthesiologists will help make life-saving cardiac care more accessible to children across India. Early detection, timely treatment, and long-term care can greatly improve the survival and quality of life of children born with congenital heart defects.

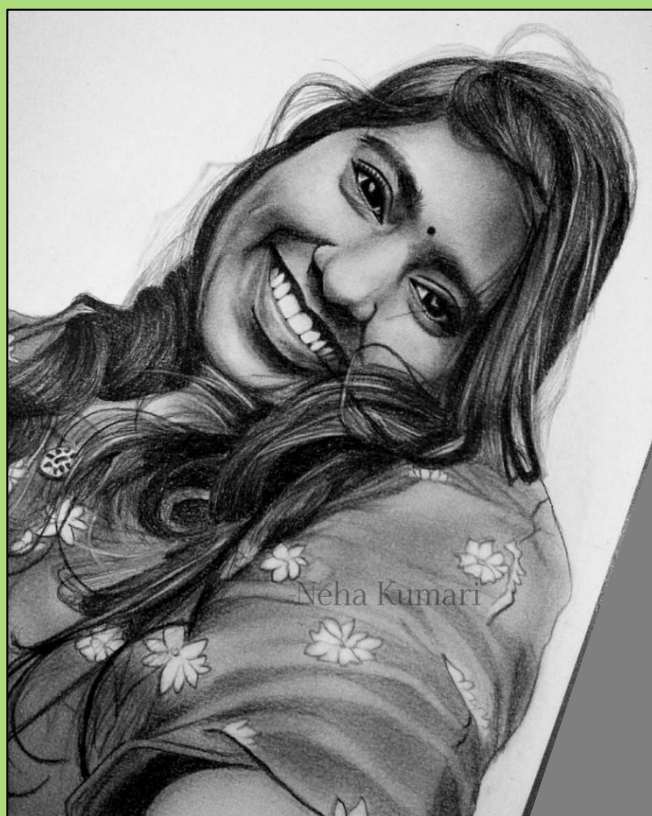
OUR CREATIVE KIDS



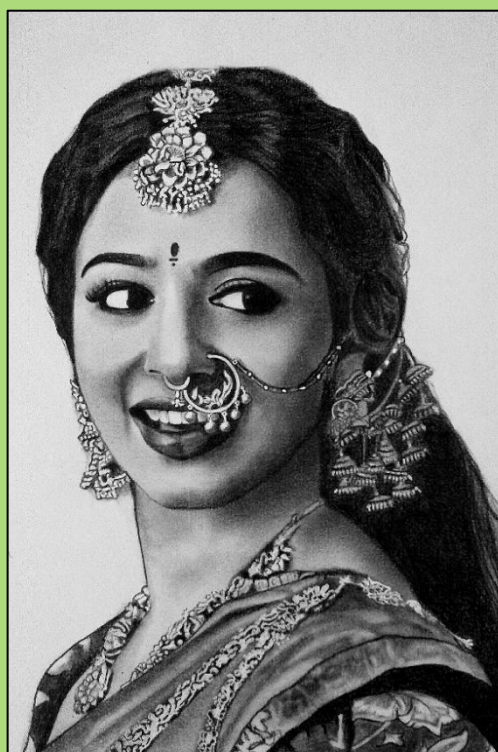
Yuvraj, 10 years



Ayushman Parth, 11 years



Neha Kumari





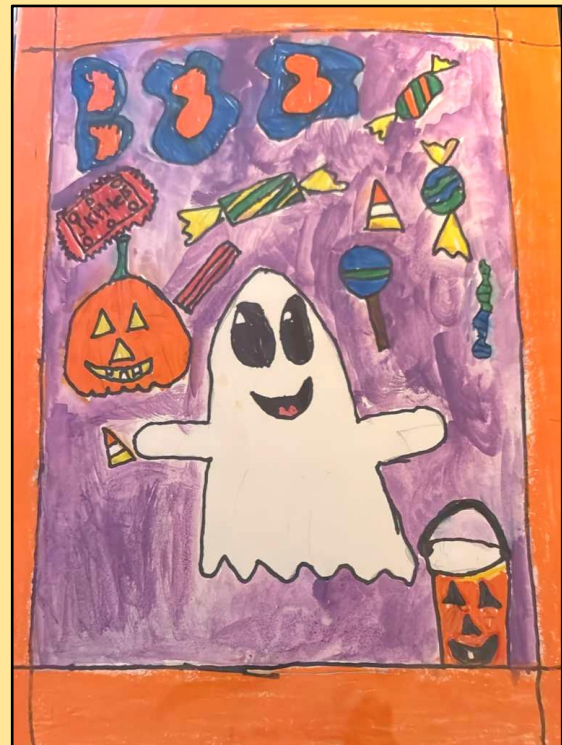
Adhiroha, 6.5 years



Ethan Lakra, 6.5 years



Aarna Peddi, 7 years



SECTION I

The Care Team: Beyond the Operating Room

After Choosing the Centre: How to Build a Lifelong Care Partnership with Your Child's Heart Team



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Children with congenital heart disease often begin with the search for a cardiac center with highly specialized teams. When a child undergoes heart surgery, families often remember the decision-making period with great intensity. The discussions, the second opinions, the long nights of searching for the right hospital. Choosing the center becomes a defining moment. Yet what the families discover soon is that the true continuity of care begins only after the surgery is completed. The most meaningful part of this journey is not the surgery itself, rather the long-term partnership with this team that cared for their child. This collaboration shapes the child's health, development and quality of life for years to come.

Once the surgery is completed, the most empowering step a parent can take is to understand the journey further. Every child has a unique roadmap, built around health check-ups, growth milestones, developmental monitoring and for some the possibility of future interventions. Knowing the roadmap early helps families work with clarity. It becomes important to stay in touch with your primary heart care team. This team will outline the medical milestones: when to come for a cardiac check-up, when to repeat echocardiograms or blood tests, and what parameters to track at home. In certain congenital heart conditions, future procedures whether catheter based or a planned surgery may be a part of the child's expected course. Being aware of this beforehand reduces fear and encourages planning effectively. Alongside these medical touchpoints, it is equally important to understand the developmental milestones: motor skills, speech and language, school readiness, social functioning and emotional wellbeing. A small percentage of children with CHD show specific neurodevelopmental vulnerabilities and early observation followed by intervention if required, allows for timely support. Asking questions and knowing about the future pathway and knowing what lies ahead makes care become smoother, decisions become less

overwhelming and the child's overall health; heart, mind, and development remain at the center of the story.

Staying connected with the primary heart care team

Once the surgery is behind you, staying in touch with the primary cardiac center is essential. The surgical team understands the nuances of your child's lesion and repair. They know what residual issues need more monitoring, and what changes may appear in the future.

Families often follow a dual-care pattern:

- Local follow-ups for routine checks and common concerns
- Periodic visits to the Primary heart care center for comprehensive reviews

This balance supports stability and ensures you always have the access to the team that knows your child's medical story from the very beginning.

When to go back to the main center vs local cardiologist

Once the surgery is over and the child is recovering, most families settle into a regular rhythm of follow ups with their local cardiologist. More than being practical it is also essential, especially for routine checks, minor concerns and ongoing monitoring close to home. Nonetheless your child's main surgical centre remains the "anchor point" for complex decisions, big changes, and milestone reviews. Understanding when to lean on each helps making the child's care smoother and safer.

One's local cardiologist is typically the first point of contact for day-to-day cardiac care. They are best suited to

- Review the child at periodic intervals for growth, symptoms and physical examination
- Alter medications for according to the clinical status
- Run basic assessments like blood tests, ECG, chest X-ray and echocardiograms based on assessments
- Screen during infection, fever or any small change in appetite.

Building a relationship with local cardiologist often means that he/she knows the child's school schedule, family situation and other health issues. This helps them work closely with your pediatrician, psychologist or even school to keep all aspects aligned for the child.

Meanwhile, connecting with your primary cardiac center becomes important when there is

- a significant new symptom that needs care,
- when your child is reaching a planned review schedule, such as one year after surgery, before starting school or before any sports participation,
- if there is a possibility of future procedures and decisions need to be made about them,
- if your local cardiologist has found that echo findings have changed or are uncertain,
- if there are any non-cardiac medical procedures needed.
- in case the patient is in due for any important milestone like major career decisions, relocating for studies, marriage etc.

Both local cardiologist and the primary center should work in tandem, with the first being someone who keeps the day-to-day engine running smoothly and the latter revisits blueprint adjusts the long-term design when needed. The best thing families can do is to keep both the teams informed: share reports from the main center with the local doctor and send summaries from local visits back to the main center. When everyone is on the same plane, decisions become clearer, emergencies become rarer making the child's journey feel less fragmented.

What helps during follow-up visits?

Follow-up appointments often move quickly. Being pre-prepared helps parents to make the most of the consultation.

Parents may find it helpful to ask

- “How is the heart functioning at this stage of growth?”
- “Are there any changes we should monitor over the next few months?”
- “Do we need any developmental or psychological assessments this year?”
- “Are there lifestyle, school, or activity restrictions we should be aware of?”

Short questions like these keep reviews focused and structured. It always helps to maintain a follow up diary to note down what the doctor has advised and to write reflections if required.

Recognizing when to seek help

Most children settle into a predictable rhythm of growth, play and school after the initial surgery and recovery. Yet there are moments when the body or mind signals that something needs attention. Recognizing these early signs (medical or developmental) helps families act at the right time. From a medical perspective any new change in how your child breathes, if any changes in feeding or appetite, significant changes in play or keeping up with peers should prompt a closer look. Breathlessness that appears suddenly, unusual fatigue during routine activities or a child who tires much faster than before may indicate that the heart may be working harder than it should. Blueness of nailbeds and lips that worsen during activity may suggest low oxygen saturations and merit attention. There are instances when the initial surgery is not corrective but only meant to buy time until the final surgery. Here it may be necessary to keep check oxygen saturations periodically especially if there is increasing blueness of skin. Subtle changes in appetite, poor weight gain, or falling off the growth chart are important flags. These can relate not only to the heart but also to how the body is tolerating medications, nutrition or the pace of growth after surgery. In such moments the families are encouraged to reconnect with their main cardiac center, even if routine follow-ups are done locally.

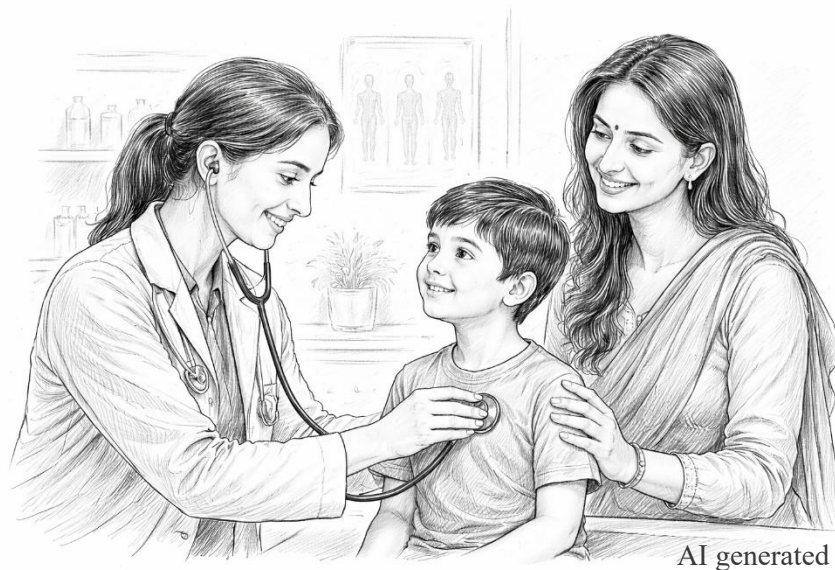
Equally important are the psychological and developmental signs. These are often overlooked because they do not look like typical “medical” symptoms. Frequent tantrums, emotional outbursts, increased irritability, anxiety, or difficulty coping are certain signs to look out for. Some children may show struggle with cognitive development like being unable to follow multi-step instructions, complete tasks on time or stay focused during classwork. This could signal possible attention or executive function challenges. Some children may show shifts in school performance, difficulty remembering what is taught, difficulty in copying what is written on the board, expressing thoughts in written form or challenges with certain subjects. Social cues also matter; trouble making friends, avoiding group work, isolating can be one way to express overwhelm or lower self-confidence. This is when it becomes essential to consult a clinical psychologist or a developmental specialist. Early assessments and interventions can differentiate between temporary adjustment challenges and more persistent neurodevelopmental vulnerabilities. Recognizing when to seek help makes one less anxious and more prepared. Today, leading cardiac centers believe that good outcomes come from many minds, not one. Surgeons, cardiologist, developmental specialists, clinical psychologists, nutritionists form the core of a child’s long term support system. Each specialist watches a different aspect of the child’s growth. A developmental specialist monitors age specific development, a clinical Psychologist focuses on cognitive, emotional and behavioral development, a nutritionist tracks appetite and growth. Together, building a complete

picture, far beyond the surgical repair. For families, this multidisciplinary structure offers a clear message: *Your child's heart is important, but so is the child as a whole.*

A partnership that evolves with your child

Over the years, your child will evolve and so will their needs. A feeding challenge of the toddler may give way to a school goer's question about sports participation. A young child's emotional needs may later shift focus to or their academics, friendships or self-esteem. Through each of these phases, what sustains families most is the reassurance that they are not navigating through any of this alone. The heart team that once focused on your child's surgical outcome becomes a guide through their developmental, emotional and academic journey as well.

A strong partnership means having the courage to ask questions, the willingness to share small worries before they become big and the openness to involve every professional who can strengthen your child's trajectory. It also means recognizing your own role, as parents are the first to notice subtle shifts in energy, behavior or learning. Your observations shape decisions more than you realize. What lies ahead is a living roadmap that adapts as your child grows. Families who remain informed, involved and connected find that this path becomes less intimidating and more empowering with time.



AI generated

From PICU Nights to Lifelong Hearts:

A Pediatric ICU–PA’s Two decade

Journey Through Congenital Heart Care



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Introduction - where the surgery ends, care begins

Congenital heart disease care does not end with surgery. It evolves through childhood, adolescence, and adulthood, carried forward by teams that treat physiology, development, lungs, kidneys, infections, nutrition, psychology, school, and the emotional ecosystem of families.

I have lived this evolution from the bedside for over two decades —not as a distant observer, but as a pediatric ICU Physician Assistant (PA), in a role that demanded clinical ownership, constant vigilance, and collaboration that crossed specialty borders long before “multidisciplinary care” became a fashionable phrase on posters.

Early years - learning the language of the ICU

My institution was a pioneer, consistently setting benchmarks far ahead of others in the country. A team of highly qualified super-specialists, trained and experienced in leading centers across the developed world, brought with them the ambition to establish comparable standards in India. Together with young, driven doctors who had completed postgraduate training in their respective specialties, they created a powerful and exceptional collective. Pediatric cardiac surgery was already advancing rapidly, but for many, ICU care was still seen as a short epilogue to a surgical triumph.

I walked into the pediatric ICU as an intern more than twenty-two years ago, for my first duty, a night shift with equal parts of curiosity and terror. It took only a few nights in the PICU to understand the punchline: *surgery repairs anatomy; the ICU rehabilitates destiny*. The pediatric

ICU teaches you to read patterns long before it teaches you to follow protocols. Some seniors believed physician assistants could never develop meaningful expertise early in their careers. Both the PICU and I proved otherwise. Children deteriorate rapidly, but their bodies whisper warnings long before they shout!! A toe cooler than usual, a subtle shift in breathing rhythm, a ventilator waveform suddenly too perfect, CVP rising unapologetically, or urine output fading like a timid goodbye.

In these early years, I learned to read physiology directly, at eye-level. I learned that ventilation is not a setting, but venous return preservation. Blood pressure is not a number, but perfusion adequacy. Saturation is a contract between lungs, hemoglobin, heart, and resistance ratios we must constantly renegotiate.

A pivotal night - when numbers misled, physiology spoke

In postoperative children, “acceptable vitals” is a dangerous compliment. A 10-month-old child after a Tetralogy of Fallot correction surgery showed normal heart rate, near-stable blood pressure, but cold extremities, increasing CVP, dipping urine output, and incessantly crying at 2 AM was never going to be normal. Numbers reassuringly lied. The child truthfully protested. The supervising anesthesiologist hesitated to intubate the child. My contribution that night wasn’t the blade - it was the insistence that physiology was decompensating regardless of the politeness of “acceptable” vitals. That insistence pulled seniors into the room and the child into survival.

That night taught me humility, priority, and hierarchy - bedside observation, physiology interpretation, early escalation followed by data, decisions, and finally action. The ICU saved the physiology long after the surgeon had saved the anatomy. Those early years taught me that patient advocacy isn’t a privilege - you borrow it from crises and repay it with sleeplessness.



Beyond the ICU - the long-term journey of CHD

Cardiac repairs survive the ICU, but physiology learns to survive the child only later. Once, a 6-year-old returned two years after his single ventricle palliation surgery, not for a “heart” reason, but for pneumonia. For a surgery that was predominantly extracardiac (outside the heart) with no or minimal requirement of medications to support the heart, and for which normal spontaneous breathing benefits more than mechanical ventilation, we were in a spot where we had to use every weapon in our arsenal. His saturations plunged, and perfusion wilted fast. His father said, “No one told us lungs would decide so much about his heart so many years after the surgery.”

That night wasn’t cardiology or cardiac surgery. It was intensive care - ventilation strategy without venous theft, pulmonary care to adjust the PVR, fluids to protect preload, antibiotics administered like armor, cardiac output curated by physiotherapists proudly recruiting lungs, infection-control literacy quietly winning long battles, and monitoring that respected trend before threshold. Battles like these were won in hours initially and then in days/nights.

Parents - the uncredentialed long-haul clinicians

Families always evolve into the child’s first long-term intensivists. They track growth, feeding endurance, fatigue timelines, saturation losses during colds, physiotherapy cycles, dental hygiene before endocarditis fear begins, infection seasons with more seriousness than birthdays, school reintegration emotions more complex than echo labels, pre-procedure antibiotics planned like rituals, milestones recorded like celestial events.

Parents don’t just want discharge. They want a care universe that continues - lungs that stay recruited, kidneys that stay perfused, brains that stay oxygenated, wounds that never reopen, nutrition that stays relentless, growth that stays stubborn, school that stays uninterrupted, psychology that stays unscarred despite scars.

Growth as a PA and practitioner - two decades of lived evolution

ICU care evolved technologically with smarter monitors, more revealing arterial and ventilator waveforms, more simple and effective non-invasive devices to monitor meaningful invasive parameters (ETCO₂, NIRS), gentler non-invasive respiratory tools like HFNC and NIV, improved infection literacy & prevention. ECMO/VAD support shrank the mortality margins for congenital and acquired cardiac disease.

Yet the largest evolution wasn’t mechanical. It was philosophical and cognitive - data are clues, not verdicts. Physiology is context, not protocol. The biggest shift was mental! “from “protocol-

driven critical care” to “context-aware, personalised physiology care”. Multidisciplinary collaboration is mandatory, not ceremonial. *The true endpoint is age-appropriate life, not hospital discharge!*

As a PA, I had to wear many hats - bedside executor, monitor-interpreter, mentor to younger colleagues, quality analyst, communicator with anxious families, liaison with surgeons, anesthetists, physiotherapists, dieticians, and other care providers. It was exhausting, often thankless, but ultimately profoundly rewarding. I realise now that PAs are the silent scaffolding of modern pediatric critical care in settings where specialists are few and burden many.

The ICU Curtain Falls - Abrupt, Unplanned, Not My Hand

In early 2025, my beloved PICU chapter ended unceremoniously, not from clinical outcomes or competence, not from error, not from anything I authored. It simply arrived, indifferent to chronology or fairness. The ICU taught me to read trends before thresholds, yet my own career wasn't granted the courtesy of trending downward slowly. There were no long farewells, no ceremonious final rounds - just the silence after a monitor gets unplugged.

The pediatric intensive care unit was never a job to me. It was my reference frame, almost my identity. It shaped how I read growth, milestones, fragility, resilience, and the quiet heroism of families holding hope in trembling hands. It was where physiology turned into philosophy, where data gained a heartbeat, where machines hummed like guardians, and where medicine revealed its most honest form - human, uncertain, brilliant, personal. That one similarity between me and one of my favourite idols - MS Dhoni!! Just like how his ODI career began and ended with “run outs”, my PICU career began and ended with “Night duties”!!

Conclusion - the long game is the only game we have

We save children first in hours, days, and nights, then in years. Congenital heart care is sustained by teams who ask better questions together than alone. Data becomes meaningful only when interrogated. Multidisciplinary care becomes real only when delivered longitudinally. Success is not ICU exit or discharge day, but childhood uninterrupted, cognition safeguarded, lungs resilient, kidneys preload-aware, infections pre-empted, muscles rehab-ready, school triumphantly ordinary.

I carried that world with me far beyond the unit, because long after the monitors fell silent, the stories kept pulsing. I would love to return to PICU someday, because some truths persist regardless of narrative pacing - oxygen delivery, venous return, resistance balance and the fierce loyalty of clinicians to fragile physiology.

SECTION II

Beyond the Heart: Development, Mind & Milestones

ROAD TO DEVELOPMENT IN CHD



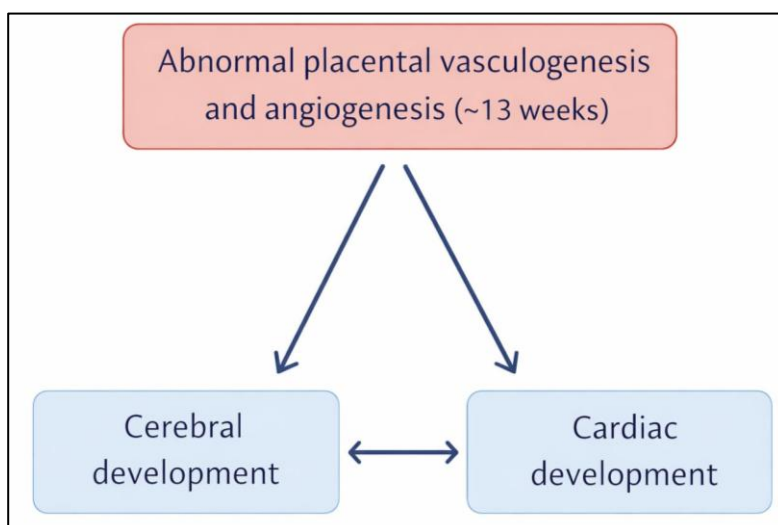
Dr. Rishika Mehta

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Congenital heart disease (CHD) is the most common congenital anomaly, and it has a strong relationship with neurodevelopmental delay in these children. Various factors have been studied for the same, especially in the last two decades, which have found a role in therapeutic implications to mitigate developmental issues. Understanding early risk factors for abnormal brain development and brain injury in CHD is of the utmost importance to develop timely interventions that may reduce neurodevelopmental impairments and improve the quality of life in these children. Early diagnosis is the first important step.

Factors affecting development in CHD: Antenatal brain development and its effects due to CHD



Cardiac development is completed by eight weeks of gestation, brain development starts from the third week of gestation and continues till early adulthood. The brain development in the fetus is strongly influenced by the presence of a congenital heart disease throughout gestation. Various factors are responsible for delayed brain development in children with CHD.

This diagram explains how early changes in the placenta during pregnancy can influence both brain and heart development in a growing baby.

Around the first 13 weeks of pregnancy, blood vessels in the placenta are forming and growing. If this process does not happen normally, it can affect how well oxygen and nutrients reach the baby.

The diagram shows that the brain (cerebral development) and the heart (cardiac development) are closely connected. Healthy development of one supports the other, and problems in early blood supply may affect both systems together. Understanding this connection helps doctors and researchers recognize why conditions affecting the placenta early in pregnancy can have long-term effects on a child's heart health, brain development, and overall well-being.

1. Hypoxic factors

Just revising briefly, in the oxygen exchange in the fetus occurs in the placenta. The oxygenated blood travels through the umbilical vein to the brain by flowing from the right atrium to the left atrium via the foramen ovale, hence any structural changes in the heart affect oxygen delivery and perfusion to the fetal brain.

In response to a hypoxic (*low oxygen*) environment in the placenta, free radicals (*harmful molecules in the body that can damage cells if not controlled*) are produced, which mediate oligodendrocyte (*special brain cells*) cell death. The decrease in this cell population causes poor myelination and decrease in the brain volume along with intrauterine growth and smaller brain size. Interventions which can decrease chronic hypoxia are potential therapeutic targets to downstream CHD-associated brain injury.

2. Placental mechanisms

Placental pathology has a direct correlation with neurodevelopment in CHD patients. In various studies, it has been found that severe placental abnormalities are directly proportional to decreased brain volume in severe CHD. In a study, it was observed that 78% of placentas in the CHD group had placental pathology compared to 28% in the control group. Placental abnormalities like placental hypoplasia, infarct, thrombosis, and chorangiosis were present in placentas complicated by CHD. These abnormalities are associated with poor fetal perfusion and have a direct relationship with lower head circumference in children with CHD.

Supporting placental function could potentially reduce acquired brain injury in CHD, thereby improving neurodevelopmental outcomes.

3. Genetic factors

A genetic syndrome or disorder is found in 20 to 30% of CHD. Underlying genetic disorders directly influence neurodevelopmental outcomes. It has been found that children with genetic syndromes like Down Syndrome, DiGeorge syndrome, CHARGE syndrome, VACTERL association, and Noonan syndrome have a smaller head circumference.

More than 40% of children born with Down syndrome have different heart defects, such as atrioventricular septal defect (ASD) or ventricular septal defect (VSD). Trisomy 21 patients have a wide spectrum of neurodevelopmental impairments, which involve motor, language, cognitive, and adaptive/social domains. In a study that describes the MRI brain in children with Down syndrome, smaller cerebral and cerebellar volumes were reported.

Seventy-five percent of patients with DiGeorge syndrome develop CHD, mostly conotruncal and aortic arch abnormalities. Along with these, DiGeorge syndrome presents with neurodevelopmental disorders, cognitive impairment, and behavioural problems like autism spectrum disorder and attention-deficit hyperactivity disorder.

4. Maternal stress

Prenatal diagnosis of CHD contributes to increased parental stress. Maternal stress, in particular, contributes to the poor neurodevelopmental outcomes. According to the ‘maternal immune activation hypothesis’, the fetal brain is exposed to various cytokines due to the maternal immune response to stress, which causes neurodevelopmental problems. Alterations in the maternal hypothalamic-pituitary-adrenal axis, like the abnormal transfer and deactivation of cortisol from mother to fetus, negatively impact neurodevelopment.

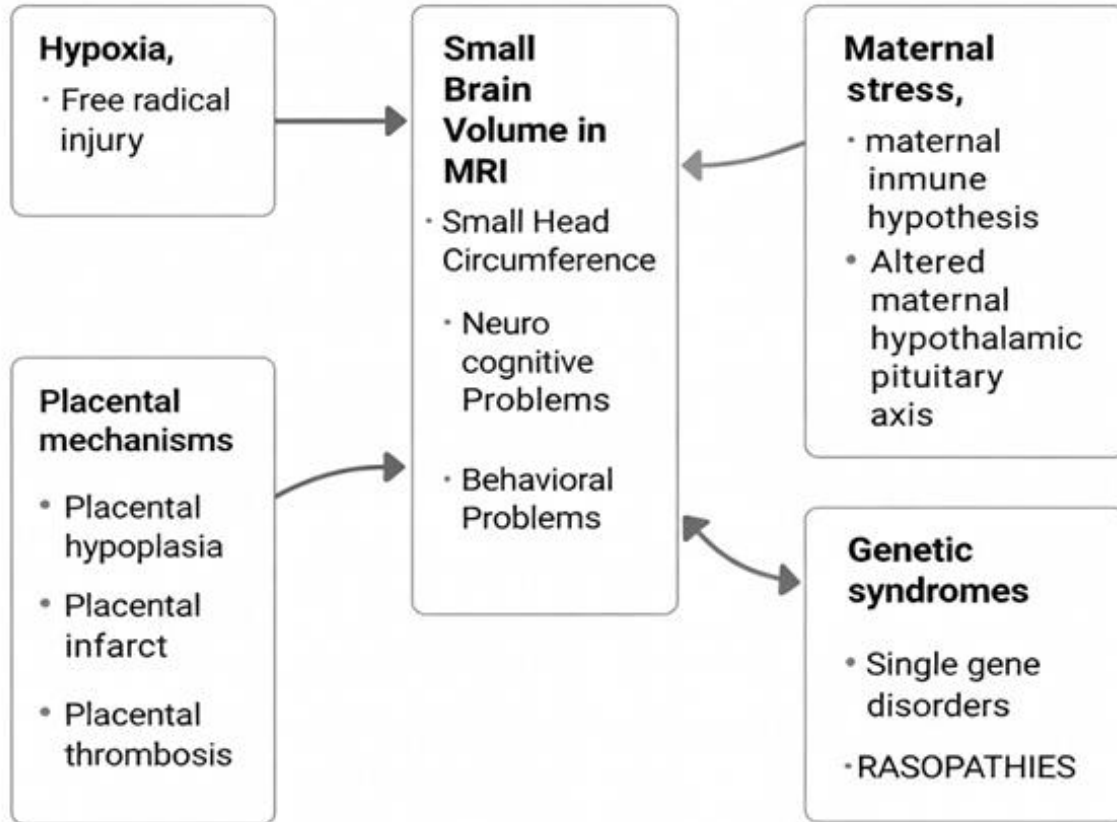
Optimising and continuing parental support from the time of CHD diagnosis may have therapeutic implications for long-term neurodevelopment.

Surgical factors related to neurodevelopmental outcomes:

1. Perioperative convulsions

In a recent multicenter study, seizures occurred in 7.4% of neonates after cardiac surgery, which were detected only by continuous electroencephalographic monitoring. Seizures cause adverse neurodevelopmental outcomes as they are supposed to cause significant brain injury. When

teenagers in this group were followed up, it was observed that at 16 years of age, academic achievement, memory, executive function, visual-spatial function, and social cognition was below average.



Factors influencing brain growth and development in children with congenital heart disease

2. Prolonged hospital stays

Prolonged hospitalisation post-surgery badly affects neurodevelopmental outcomes due to various factors, most common ones amongst them being hypoxia, hypotension, prolonged inflammation, hormonal imbalances, frequent feeding disruptions, obnoxious stimulations to bright lights and noise, along with lack of positive stimulation and parental separation

3. Cardiac arrest and resuscitation

Global hypoxic-ischemic brain injury may occur after cardiac arrest due to extreme hypoxemia and hypoperfusion, which is associated with worse neurodevelopmental outcomes.

The AHA 2024 Scientific statements state that children who had cardiac arrest, which needed chest compressions for a minimum of 2 minutes and were ventilator dependent had a highly unfavourable 12-month adaptive functioning. Only 37% with in-hospital arrest and 16% with out-of-hospital arrest had better outcomes

4. Heart transplantation

Adolescents who underwent heart transplantation during infancy showed substantial impairments in cognitive functioning, motor and visual integration, receptive and expressive speech, and executive functioning, making their independent ability questionable.

The age-based developmental evaluation should be done as follows:

Infancy	→ School Age and Teenage	→ Early Adulthood
• Feeding and sleeping • Milestones • Fine and gross motor skills • Social and adaptive skills • Emotional behavioral functions	• Intelligence • Academic functions • Attention and memory • Executive functions • Speech language • Emotional and behavioral functions	• Work social and developmental history • Memory • Language • Executive functions • Social and adaptive skills

Any deviation from these parameters should urge the parent to see a developmental pediatrician.

Neuroprotective strategies for better outcomes

1. Fetal and perinatal neuroprotective strategies

Early prenatal detection of heart diseases, helping in early intervention, planning for an uncomplicated full-term delivery, early detection of syndromic genetic association, maternal

hyperoxygenation are a few proven early neuroprotective strategies that may prevent developmental delays.

2. Surgical and perioperative neuroprotection

Appropriate timings of surgery, minimising deleterious effects of CPB, monitoring cerebral perfusion, and providing appropriate oxygenation, and good technical operations are healthy neuroprotective strategies.

3. Social factors

Providing support to caregivers, early stimulation, physical and mental rehabilitation strategies, care coordination, and family centred approach to care of a CHD baby is very important for good neurodevelopmental outcomes

Conclusion

Though there have been dramatic advancements in medical and surgical outcomes, the neurodevelopmental outcomes in CHD patients have not improved meaningfully. These individuals have negative impacts on academic achievement, employment, independent living, and quality of life, and hence pose a heavy burden on individuals, families, communities, and society, particularly as this patient population grows and ages. It is essentially important for health care professionals and researchers to identify neuroprotective and intervention strategies that shall mitigate developmental delay and improve the quality of life in these individuals.

The Blueprint of Bloom: Nurturing Mind's Milestones



Ms. Lopamudra Das Gupta

MPhil 1st year Trainee

Ex-Psychologist at Nabajatak Child Development Centre &
Child Development Centre, Apollo Multispeciality Hospitals, Kolkata

From silent cells that gather in the womb,
A tender heart assumes its destined bloom.
But when the blueprint carries flaw and twist,
A lifelong journey starts, forever kissed
By shadows of a health defined as frail,
The Congenital Heart Disease (CHD) trail.
A road that asks for courage, grace, and might,
And guides the family through the darkest night.

It is a world of surgeons, skilled and bold,
Where complex stories on the screen unfold.
Of cardiologists who chart the flow,
And monitor the life they help to grow.
Yet healing is a craft of many hands,



And greater care the growing child demands.
For fragile hearts impact the oxygen's supply,
And shape the ways the eager brain draws nigh.

The months tick on, and sometimes we can find,
The body lags a step behind the mind.
The usual bright procession of the growth,
Is stalled by subtle, undeniable sloth.
This is the moment, parent, keen and sharp,
To read the notes upon the body's harp.

The Red Flags rise, a crucial, urgent plea:
The little milestones fail consistently.
A weak neck struggles, poor head control is plain,
The effort to sit up feels like a heavy chain.
The curious hands, which should begin to grasp,
Are slow to learn the delicate clasp.
Fine motor skills and coordination wane,
A symptom whispered by the heart's own strain.

Look closely when the speech is taking flight,
If words are few or slow to gain their height.
The weary child whose playtime must decrease,



Exhausted by the quest for inner peace.

The physical fatigue that dampens play,

And steals the energy of every day.

This multidisciplinary road is long,

And where the heart is weak, the brain must be strong.

But strength must be ignited, lit with speed,

To plant the vital therapeutic seed.

For brain development is time's strict race,

And every lost week leaves an empty space.

When red flags signal worry, clear and deep,

While specialists the complex heart do keep,

The path must turn, with immediacy of call,

To seek the doctor who can manage all.

The Developmental Paediatrician knows,

The subtle way the CHD shadow grows.

They bridge the gaps with interventions well-planned,

To aid the walking, speaking, thinking land.

The Developmental Pediatrician's wisdom, timely sought,

Ensures that swift and vital aid is brought.

For early detection followed by the care,



Of early intervention's specialised repair.
With interventions for language, strength, and thought,
A potent bridge to better growth is wrought.
We cannot wait for progress to take hold,
We must equip the future, brave and bold.

Do not delay, for early help will mend,
The future path upon which all depend.
To heal the heart is half the victory won,
To nourish mind and body under the sun,
Is to complete the journey, whole and true,
And give the child the best they're destined to do.
You can also seek the help that expertise can lend,

From Nabajatak Child Development Centre's end.
With trained group of multidisciplinary professionals led by a Developmental Paediatrician,
their science thrives,
Where the Kolkata Developmental Model transforms young lives.
For children struggling, facing tough defense,
They master challenges with keen competence.
A promise shown: eighty-five percent's success,
To join the mainstream, shedding all distress.



Parent Questionnaire: Early Development & Health Screening

Ms. Lopamudra Das Gupta, Clinical Psychology Trainee

Ms. Megha Goenka, Early Interventionist and Psychologist

Dr. Anjan Bhattacharya, Consultant Developmental Pediatrician

This questionnaire has been framed based on established developmental screening indicators and clinical references, and adapted for parent understanding, and was designed by Dr. Anjan Bhattacharya, developmental pediatrician at Apollo Multispeciality Hospitals, Kolkata; Ms. Megha Goenka, early interventionist and psychologist; and Ms. Lopamudra Das Gupta, clinical psychology trainee. It is designed to help parents reflect on their child's early health and developmental experiences in a simple and structured way. This tool is intended as a supportive guide, not a diagnostic instrument.

By answering these questions, parents and caregivers may gain better insight into whether their baby or young child is meeting expected developmental milestones, or whether there are early signs that suggest the need for additional support. Children with congenital heart disease (CHD) may have unique developmental journeys, and early identification of concerns can make a meaningful difference.

If this questionnaire raises any worries or uncertainties, parents are encouraged to discuss their responses with their pediatrician or seek an early referral to a Developmental Pediatrician or Early Intervention team. Early guidance does not mean something is “wrong” — it simply helps ensure that every child receives the right support at the right time.

SECTION A: Pregnancy & Birth History

Was your baby born before 37 weeks of pregnancy?

☐ Yes ☐ No ☐ Not sure

Was your baby's birth weight less than 2.5 kg or was growth restricted during pregnancy?

☐ Yes ☐ No ☐ Not sure

Did you have anemia (low hemoglobin) during pregnancy?

☐ Yes ☐ No ☐ Not sure

Did you have thyroid problems (high or low thyroid levels) during pregnancy?

☐ Yes ☐ No ☐ Not sure

Did you take any long-term medications, alcohol, tobacco, or other substances during pregnancy?

☐ Yes ☐ No

If yes, please specify: _____

Was the pregnancy through assisted reproduction (IVF/ICSI)?

☐ Yes ☐ No ☐ Not sure

Were there any abnormal findings on antenatal scans?

☐ Yes ☐ No ☐ Not sure

Did you have a previous pregnancy with complications, stillbirth, or neonatal death?

☐ Yes ☐ No ☐ Not sure

SECTION B: Delivery & Newborn Period

Did your baby cry immediately after birth?

☐ Yes ☐ No ☐ Weak/feeble cry

Was your baby's APGAR score low or did doctors express concern at birth?

(APGAR score: a simple health check done in the first few minutes after birth to assess breathing, heart rate, movement, reflexes, and skin color.)

☐ Yes ☐ No ☐ Not sure

Did your baby need admission to the NICU?

☐ Yes ☐ No

If yes, duration: _____

Did your baby need oxygen support?

☐ Yes ☐ No

Did your baby need ventilation?

☐ Yes ☐ No

Did your baby have breathing problems after birth (RDS, meconium aspiration)?

☐ Yes ☐ No

Did your baby have severe jaundice requiring treatment?

☐ Yes ☐ No

Did your baby have low blood sugar (hypoglycemia)?

☐ Yes ☐ No ☐ Not sure

Did your baby have seizures / fits / convulsions in the newborn period?

☐ Yes ☐ No

Was your baby treated for infection, sepsis, or meningitis?

☐ Yes ☐ No

Was there any history of lack of oxygen (hypoxia) around birth?

☐ Yes ☐ No ☐ Not sure

SECTION C: Brain & Neurological Concerns

Has your baby ever been diagnosed with:

- Brain bleed (IVH)? ☐ Yes ☐ No
- Brain injury due to lack of oxygen (HIE)? ☐ Yes ☐ No
- Hydrocephalus (fluid in the brain)? ☐ Yes ☐ No

Does your baby often seem:

- Very floppy or unusually weak? ☐ Yes ☐ No
- Very stiff or arched backwards? ☐ Yes ☐ No
- Excessively alert or irritable? ☐ Yes ☐ No

Does your baby have feeding difficulties (poor sucking, latching, or tiring easily)?

☐ Yes ☐ No

Does your baby have unexplained excessive crying, especially dislikes being held?

☐ Yes ☐ No

Does your baby appear jittery or shaky without a clear reason?

☐ Yes ☐ No

Has your baby ever had a sudden event where breathing stopped, turned blue, or became limp (ALTE)?

☐ Yes ☐ No

SECTION D: Growth, Appearance & Genetic Concerns

Has your baby been diagnosed with a genetic syndrome (e.g., CHARGE or others)?

☐ Yes ☐ No

If yes, name (if known): _____

Have doctors mentioned unusual facial features or body differences?

☐ Yes ☐ No

Has your baby been described as a “special needs” or “specially cared for” child?

☐ Yes ☐ No

Is there a family history of:

• Neonatal death / cot death? ☐ Yes ☐ No

• Genetic or metabolic disorders? ☐ Yes ☐ No

SECTION E: Heart & Medical Conditions

Has your baby been diagnosed with a congenital heart defect (CHD)?

☐ Yes ☐ No

If yes, type (if known): _____

Does your baby tire easily during feeding or show bluish discoloration?

☐ Yes ☐ No

SECTION F: Parent Concerns (Very Important)

Do you have any concerns, doubts, or anxiety about your child's development or behavior?

☐ Yes ☐ No

Would you like your child to undergo developmental screening or assessment?

☐ Yes ☐ No

SECTION III

The Parenting Journey

“The Child Who Taught Me Courage: Our Life with Congenital Heart Disease”

Ms. Vibha Dhoot

CHD Parent

Jaipur, Rajasthan

My journey as a CHD parent began the day my son was born in 2016 — a day that should have been filled with celebration, but instead tested every fibre of my existence. Mine was a full-term pregnancy. Every scan, every sonography, every report had shown that everything was normal. No one suspected even for a moment that my baby carried a complex and life-altering condition in his tiny heart.

But the moment he was born, he was blue. He was rushed to the NICU before I could even hold him. Within hours, doctors discovered major and multiple heart defects. I had just undergone a caesarean section, so the severity of his condition was not fully revealed to me. For 11 days, I lived in partial understanding, unaware of the gravity of what was happening — until the moment I accidentally saw messages on my husband’s phone. That was the moment my world stood still. He had Pulmonary Atresia with MAPCA’s along with VSD

The first 24 hours after birth were crucial, doctors said. Then it became “72 hours are critical.” Then “one week is important.” But the truth was — every hour felt like walking on thin ice. His oxygen saturation stayed below 70. We were told he couldn’t cry too much; it could strain his heart. Every night was a test of courage. As a mother, I went to sleep not knowing if my child would still be with me the next morning. And every morning, I thanked God simply for letting me see his face again.

When all of this happened to us, a painful question echoed in my mind — *Why me? Why him? Why our family?*

But the moment we reached the hospital, our perspective shifted. We realised we were not alone. There were hundreds of children battling heart conditions, undergoing critical surgeries, fighting for life with unbelievable courage. Babies just a day old were on ventilators. That sight shook my soul. For the next 17 days that we spent in the hospital, all these families became our extended

family. We shared our fears, our tears, our prayers. Our griefs were halved, our strength was doubled.

At eight months old, my son finally underwent his first open-heart surgery — a 12-hour ordeal from 9 a.m. to 9 p.m. Those hours felt like a lifetime. We were losing hope, fighting fear, praying silently. Then came the words we had begged to hear:

“The surgery was successful.”

He spent 17 days in the hospital recovering. Most repairs were done, except one which would require correction every 5–6 years. That meant he would need open-heart surgeries throughout his life. Accepting that reality broke me — but loving him gave me strength.

Soon after, another challenge surfaced. Post-surgery, he developed arrhythmia. After a year of observation, doctors confirmed he would need a pacemaker for life. At barely one year old, my little boy underwent another surgery to have a pacemaker placed in his abdomen.

By April 2024, he had his **third** major surgery — again an open-heart procedure — to replace the conduit between his heart and lungs. This artificial pathway will need replacement every few years, meaning the journey is ongoing.

Physically, his growth has been slower. His weight and height are far below average for his age. But his mind? Sharp. Bright. Extraordinary. He is among the top students in his class, curious about everything, eager to learn, eager to live.

What often hurts are the reactions of people — the pitying looks, the whispered comments, the unfiltered words like “weak,” “bechara,” “kamzor.” These sting more than anyone realizes. For them it’s a moment; for us it becomes a memory.

But my son continues to rise above it all.

I have never met a braver child.

Just two days after one of his surgeries, he was asking for a chessboard on his hospital bed. His smile, his courage, his spirit — they redefine strength for me every single day.

Our CHD journey is lifelong. The struggles are real, continuous. But the joy this child brings — the happiness, the pride, the miracle he is — is priceless.

And none of this journey would have been possible without the doctor who guided us, healed our son, and stood like a divine force through every step.

We owe our child's life to a doctor who is nothing less than a God to us.

I share this story not for sympathy, but to create awareness. To help other parents feel seen. To tell the world that children with CHD are not weak — they are warriors. And their parents learn to become warriors too.

My son may carry scars on his chest, but those scars are symbols of his fight, his survival, and his extraordinary courage.

Every day, he gives me a reason to believe in hope, in goodness, and in miracles.

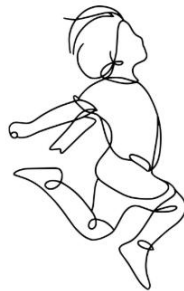
To My Brave Little Heart

You came into my world so tiny, so new,
Yet carried a strength I never knew.
Your heartbeat battled, your spirit soared,
A warrior child the heavens adored.

Your scars shine bright like stars in the night,
Each one a story of courage and fight.
You taught me hope, you taught me grace,
You taught me love has its own brave face.

When people see weakness, I see your fire,
Your smile, your dreams, your endless desire.
My little hero with a mighty start —
You are my joy, my pride, my brave little heart.

If life is a battlefield, you are my sword,
If miracles exist, you are my reward.
And as long as I breathe, I promise you this —
You'll always be held in a mother's warm bliss.



Challenges in Parenting a School Going Kid with Congenital Heart Defects

Ms. Jonali Choudhury

CHD parent

Guwahati, Assam

When a kid with congenital heart defects (CHD) is 3 or 4 years old, we search for a good school. I preferred a school with maximum facilities and minimum pressure on reading and writing. I was able to find a preschool as well as a school for my child. Most of the teachers of both institutions are helpful and sensitive. My child does not go to school regularly. The school authority has allowed this. But I have learned that there are schools that do not admit a child after knowing about the congenital heart defects of the kid. Not only as a mother but also as a teacher, I believe schools should have a friendly policy for a kid with congenital heart defects.

Many kids with congenital heart defects don't need any special care at school. But those with a complex heart defect or a recent surgery might have problems such as fast breathing or shortness of breath, or bluish colouring. They might need to keep a water bottle to stay hydrated or to stay indoors on hot days. Some might need to go to the bathroom a lot if they are taking a diuretic. Some might miss classes to see their cardiologists. Some even might have developmental delays or learning problems. [1]

Some kids or their parents may want their privacy, and some others may feel more open about it. Even some may want to discuss about their condition.

Dear teachers, to help your students with CHD succeed in school, you can give them extra time to finish school work, let them do fewer assignments, and allow them to take online tests if needed. [1]

Once the schooling starts, if the kid enjoys studying and going to school then it is well and good, *but what if the kid does not enjoy?*

Obviously, a parent cannot pressure the child to study hard. But the surrounding forces the child. There is pressure from everywhere else. Forget about the academics, there is pressure for other

activities as well. Some of the CHD kids excel in academics, some sing with great skill, some play at a top-notch level, and some neither play nor dance nor even understand well. School teaches competition, which is good. Kids learn to compete - that is also good. And then they don't like to lose. They don't want to lose by including someone weak in their team. And thus, our kids feel excluded. I don't know where the fault is.

The question here is, are our CHD kids dull compared to their heart-healthy classmates?

Lots of studies are done on this topic. Some research shows that the CHD kids are more likely to have neurodevelopmental deficits, take part in special education classes, and are less likely to complete higher education.[2] CHD kids are at increased risk of developmental disorders, disabilities, or developmental delay.[3] A literature review (publications from January 1990 to January 2019) suggests that infants with a single ventricle are at higher risk of adverse developmental outcomes. [4]

Understanding what is taught might not be a problem for the CHD kids. But as they get older, their responsibilities in the process of learning increase.[1] They have to be able to manage the time in the classroom or in the examination hall, and they must learn self-organisation and a lot more other things.

We can remember what people experienced during COVID-19 when their oxygen saturation dropped down the 90-95. And our kids are laughing, playing, and studying with 80% saturation. *This hurts.* Persisting cyanosis is associated with gross motor delay. [5] And on the improvement of hypoxia the neurodevelopmental status also improves.[6] But kids which complex cyanotic CHDs are with hypoxia for a significant duration of their lives.

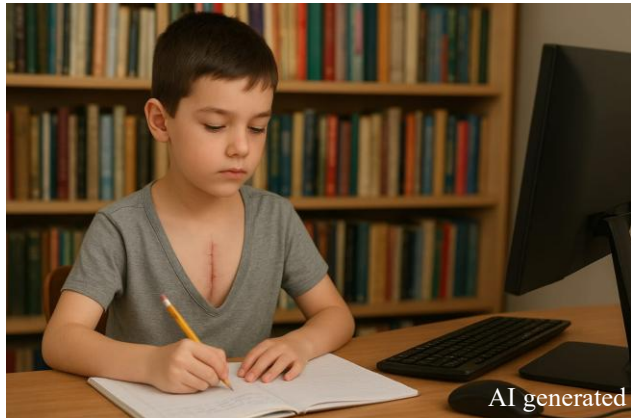
Some studies say that the motor skills are more affected by CHD in general than the mental skills and cognitive function.[7]

I asked some CHD parents and adults with CHD about their kids' (or their own) education. 77 replied. Out of them, 25 (14 with single ventricle) said that their children are below average. 14 (6 with single ventricle) is average, and 36 (22 with single ventricle) are doing amazing. My random, disorganized data shows 46% are doing amazing. (But this can be a result of the fact that parents feel reluctant to respond when the kid is not doing well.)

Even if we are not sure whether the neurodevelopmental deficits are caused by CHD or not, we're pretty sure that there are many more problems faced by these kids while going for education. They have to miss their classes frequently. We, the parents, cannot afford a little risk of infection. So with the slightest sign of a cold or runny nose, we prefer to keep them at home. They miss their

classes due to hospitalisation or even for routine checkups. If a surgery is scheduled, they cannot attend school for a long period, sometimes for months. With so much irregularities in attendance they have to compete with the healthy regular classmates.

Generally, if you are good at academics, you can choose a job of your choice. For our CHD kids, we need placement with less labour and more relaxation. But to choose, they need to excel in studies. And to excel, they need to study regularly and study hard. So, it becomes a vicious cycle.



Being a CHD mother, I want my kid to take no mental or physical stress. But at the same time, I'm worried about the future of my kid. Being a teacher, I want all students, including my own CHD kid, to excel at their academics. So, I'm always in a dilemma, up to what extent CHD kids should work hard and how often, how long they should relax!

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My Emotional CHD Nutrition Journey: Feeding my Daughter with Hope, Fear, & Love

Ms. Pritisudha Sharma Bhowmick

CHD Parent

Barrackpore, West Bengal

Becoming a mother is supposed to feel natural — feeding your baby, watching them grow, celebrating milestones. But when my daughter was born with congenital heart disease (CHD), feeding became something entirely different. It wasn't just nourishment. It wasn't routine. It became a responsibility that carried fear, guilt, determination, and an overwhelming amount of love.

From the very beginning, her feed intake was low. She would latch or drink for a few minutes and then tire out completely. Her tiny body would give up before her hunger did. I could see it — her heart working harder than it should, even during something as simple as feeding.

While other babies fed and slept peacefully, I lived by the clock.

Every two hours — day and night — I fed her. There were no long stretches of sleep. No “rest when the baby rests.” I set alarms through the night, sometimes waking her gently, sometimes crying quietly beside her crib before picking her up. I knew she needed those calories. I knew missing feeds wasn't an option.

Some feeds went smoothly. Many didn't.

Sometimes she barely took anything, and I would sit there staring at the bottle, calculating in my head whether it would be enough. I remember feeling helpless — wishing I could transfer my strength into her tiny body.

But I stayed consistent. Two-hourly feeds for 24 hours. Over and over again.

That phase taught me my first and biggest lesson: for a CHD child, small and frequent feeds are life-saving. When they cannot take much at once, you give them little — but often. You don't give up.

When we began our solids journey, I felt hopeful. Maybe this would be easier. Maybe she would eat better.

But I quickly realized that with CHD, quantity is rarely the answer — quality is.

Her weight had always been on the lower side. Growth charts became emotional triggers for me. I didn't just see numbers — I saw effort, sleepless nights, prayers, and worry.

So, I changed my mindset. Instead of asking, “How much did she eat?” I started asking, “How nutritious was each bite?”

I began focusing only on high-calorie, nutrient-dense foods. Every meal had to work harder because she couldn't eat large volumes. I enriched her food carefully — adding ghee in moderation to her khichdi, mixing nut powders into porridges when age-appropriate, choosing full-fat dairy, including bananas, rice, potatoes, lentils, and other energy-dense options.

Protein became a priority — eggs, dairy, pulses, dals — because her body needed strength to support her heart.

Each spoonful mattered.

There were days when she gained a few grams, and I felt like celebrating. And there were days when the scale didn't move, and I questioned everything I was doing.

Then came another challenge — picky eating.

Just when I felt confident about calorie planning, she began refusing foods she once loved. Carefully prepared meals would be pushed away. My heart would sink.

For many parents, picky eating is frustrating. For a CHD parent, it is terrifying.

Every refusal triggered anxiety: Will she lose weight? Will her energy drop? Is her heart getting enough nutrition?

I had to remind myself — she is still a toddler. She deserves the freedom to have preferences. So instead of forcing, I adapted.

I reoffered foods after a few days. I changed textures. I changed timing. I changed presentation.

Presentation became my quiet strategy.

The same roti she rejected? I cut it into stars and hearts. Rice became small bite-sized balls. Vegetables were arranged like a rainbow — green peas, orange carrots, yellow corn. I used molds for idlis and sandwiches. I created variety in every meal — different shapes, colors, and textures — even if the nutritional base remained calorie-rich.

Sometimes it worked like magic. Sometimes it didn't.

But I kept trying.

Because feeding her was not just about nutrition — it was about resilience.

Over time, I understood what an ideal CHD diet truly means:

- Offer small, frequent meals (every 2–3 hours) to prevent fatigue during feeding.
- Focus on high-calorie, nutrient-dense foods rather than large food volumes.
- Enrich meals with healthy fats like ghee (in moderation), butter, nut powders (age-appropriate), and full-fat dairy.
- Include adequate protein sources such as eggs, dairy, lentils, pulses, and soft meats (if non-vegetarian).
- Choose energy-dense foods like banana, avocado, potatoes, rice, and well-cooked dals.
- Fortify regular meals by adding extra calories to porridge, khichdi, roti, or mashed foods.
- Ensure a balanced plate with carbohydrates, proteins, and healthy fats in each meal.
- Monitor fluid intake if any restriction is advised by the cardiologist.
- Make meals visually appealing with colors, shapes, and variety to manage picky eating.

Track growth regularly and consult your pediatrician or pediatric cardiologist for personalized guidance

But beyond all the practical guidelines, there is an emotional reality that people rarely talk about.

Feeding a child with CHD carries invisible weight.

There are nights filled with silent prayers. There are days of comparison when you see other children eating freely without fatigue. There are moments of guilt when she refuses food, and you wonder if you could have done better.

And yet — there are moments of pure pride.

When she finishes a meal. When she tries something new. When the scale shows even the smallest increase. When she smiles after eating.

I have learned that progress with a CHD child is rarely dramatic. It is slow. It is steady. It is built on consistency and patience.

I have learned that perfection is impossible — but persistence is powerful.

Most importantly, I have learned that behind every carefully prepared meal is love. Behind every two-hour alarm is hope. Behind every enriched spoonful is a mother trying her best.

My daughter has taught me strength in ways I never imagined. Her heart may be medically fragile, but her spirit is fierce. And through this journey, I have discovered strength in myself too.

Feeding her is still not effortless. I still plan. I still calculate. I still worry.

But now, alongside the fear, there is confidence.

Because I know that every bite — no matter how small — carries intention.

And in our home, every spoonful is not just food.

It is love. It is resilience. It is hope for a stronger tomorrow.



SECTION IV

Voices of the Warriors

The Weight I Carried

Mr. Nikhil Shah

CHD warrior

Amravati, Maharashtra

For years, I used to hide that I have a Congenital Heart Defect.

It wasn't because I didn't accept it, it was because I was ashamed of it.

Whenever someone asked me to help with something that involved lifting or carrying anything heavy, I'd quickly say, "My shoulder hurts," or "My back is stiff today."

Sometimes, I would even push myself to do the work; despite knowing it would leave me breathless and exhausted.

But I never told anyone the real reason, never admitted that my heart wasn't built to handle such strain.

I avoided lifting heavy weights with my hands, but I carried a much heavier burden in my mind, the feeling of not being able to do what others found simple, normal, effortless.

And believe me, lifting a 15 kg bag at the airport is far easier than lifting the invisible weight of constant thoughts like "Why can't I do this?" or "Why am I different?"

Everything changed the day the Special Hearts of God group found me.

For the first time, I met people who truly understood, not through sympathy, but through shared experience.

People who didn't make me feel "less than", but reminded me that I was more than enough.

Now, I speak about CHD freely. My friends know why I always prefer beaches over mountains.

I have stopped blaming my fate, stopped thinking this was some punishment for past karma. It's not my fault that my heart's anatomy is different, it's simply the way I was created.

And now, the weight I carried silently for decades is finally becoming lighter, day by day, breath by breath.

All thanks to this beautiful group of hearts that beat differently, yet together.

मुश्किलों से होकर

ज़िंदगी मुश्किल नहीं होती,
मुश्किल दौर से गुज़रती है।

तुझे तो कल की फ़िक्र सताती है,
और वो कल एक नई राह बनाती है।

तेरे सब्र का इम्तिहान इसीलिए लेती है कि,
तेरे हक़ में कुछ बेहतर लिख सके।

ये ज़िंदगी है जनाब,
हर हाल में जीना सिखा देती है।

- क़ाज़ी निशात अफ़ज़ा



A New Heart, A New Benning: School to College Journey

Ms. Qazi Nishat Afza

CHD Warrior

Kota, Rajasthan

This story is not just my story; it is the story of thousands of children like me. I am a CHD patient. I have undergone three surgeries, the first when I was 11-month-old, the second when I was one and half years old and the third open heart surgery when I was 10 years old. All three of my surgeries were done in Delhi AIIMS where I still go for follow up. I never imagined that life after surgery would be so challenging—especially as my journey moved from school to college.

After the open-heart surgery, my old school refused to take me back. The teachers didn't want to teach me. And the only reason was that I had undergone surgery. They didn't understand my problem. They denied me the chance to study and I had to leave school. I took admission in another school. Due of my condition, doctors had recommended a few reasonable accommodations: late arrival on bad days, exemption from sports, extra breaks. and some teachers had a problem because I was getting special treatment. One day, a teacher hit me with a ruler without any reason, and I had to leave that school as well. I changed schools twice and completed my schooling through long distance learning and self-study. Unfortunately, the same challenges followed me into college, and I completed my graduation in the same way. I didn't expect this from teachers - they neither understood my difficulties nor made any effort to do so.

Today, I hold a degree in my hand. I know the journey behind it—the difficulties I faced and the many battles I fought to continue my education. Even today I am facing problems in my career. Like me, many children must be facing this problem and there are some children who are not able to study at all. Education is every child's right and is essential for their future.

All of this happened because of a lack of awareness, and it will continue to happen unless awareness is actively created. People living with CHD, and their families should all come together and do something to spread awareness and raise our voice for our rights, and the government must recognise these concerns and respond with supportive policies.

In India, students living with congenital heart defect (CHD) still struggle with rigid rules, lack of medical support, and limited awareness in schools and colleges. What they need is an inclusive system with flexible attendance, exam concessions, hybrid learning options, trained teachers, and in-campus medical facilities. In many developed countries, CHD students are supported through structured systems like Individual Education Plans (IEP), trained medical staff, mental health counseling, and flexible curriculums based on their health condition. *Education there adapts to the child, not the child to the pressure of education.*

India now needs strong policies and effective implementation to ensure that no child's heart condition becomes a barrier to learning. There are many children in our country who are unable to study due to this disease. And the children who are studying have to face a lot of difficulties. Illness cannot come in the way of studies. No one can stop children from studying. Studying is the right of every child.

Other countries, such as the United States and Canada, recognise children with congenital heart disease as having disabilities and provide appropriate support and accommodations for their education.

It is important to consider the needs of children living with CHD in India. If adequate academic support, flexible learning systems, and career guidance are not made available to them, it becomes difficult for these children to fully realize their potential and contribute meaningfully to society.

I would like to respectfully ask the Indian Government: **What steps can be taken to better support children with CHD in their educational journey and future career pathways, so they too can be empowered as part of the country's future?**

Right to Education in India

Article 21-A of the Constitution and the RTE Act, 2009 make free and compulsory education a fundamental right for all children aged 6–14 years. The law places a legal duty on governments to ensure admission, attendance, and completion of elementary education without financial barriers. It also mandates minimum school standards, trained teachers, child-friendly learning environments, and prohibits physical or mental harassment—ensuring safe, equitable, and inclusive education for every child.

Growing Up with Congenital Heart Disease and Pulmonary Hypertension: More Than a Physical Journey

Mr. Ganesh Kumar Anegondi

CHD & PH warrior

Rayachoty, Andhra Pradesh

I was born with a **ventricular septal defect (VSD)**. From early childhood, my life was shaped by frequent illness, breathlessness, and limitations that were not always visible to others but were deeply real to me.

Because of my heart condition, my parents were understandably protective. I was discouraged from running, lifting weights, or participating in most sports. While other children played freely, I learned early to measure my actions and conserve energy. Even when I tried to be involved — playing cricket, kho-kho, or kabaddi — I would quickly feel out of breath, a reminder that my body worked differently.

Over time, I adapted by choosing activities that required less physical effort. What I did not realize then was that this constant self-monitoring would shape not only my physical life, but also my **confidence, personality, and emotional world**.

The Emotional and Psychological Impact of CHD

Living with congenital heart disease did not just limit my physical activity — it affected how I saw myself.

I gradually became more introverted, not because I lacked interest in people, but because attention felt risky. Situations where I was in the spotlight — addressing a school assembly or speaking in front of a group — would trigger intense physical reactions: a racing heart, a blank mind, overwhelming anxiety. Even when I knew I was capable, I often avoided opportunities simply to stay safe.

Social interactions, including relationships with the opposite gender, were limited. Making friends felt difficult. I learned to stay in the background, not because I wanted to disappear, but because being noticed meant exposing my vulnerabilities.

Looking back, I can see **how CHD shaped my emotional development as much as my physical one.**

A Father's Silent Fear

My father was a tough man who worked as a lorry driver. He rarely showed his emotions.

Before my VSD closure surgery at Sri Sathya Sai Institute of Higher Medical Sciences, Puttaparthi, the hospital asked my parents to sign a consent form explaining that, in extreme situations, they could not guarantee my life.

Because caretakers were not allowed to stay at night, my parents had to return to the small room they had rented nearby. I was alone in the hospital.

A few days after the surgery, my mother told me what happened that night. My father did not sleep. He sat quietly in the room with red, teary eyes. He did not speak much. He simply waited.

At that age, I did not understand what this meant. Only later did I realize the fear and helplessness my parents were carrying — trusting others with their child's life and having no choice but to wait.

My father is no longer with me. But this memory reminds me of the silent strength and love that supported me long before I was old enough to recognize it.

Family, Responsibility, and Invisible Sacrifices

After my VSD closure surgery, my younger brother was asked to carry my school bag along with his own. Even as a child, I felt deeply guilty — as if my condition was physically weighing him down.

That sense of responsibility did not end there. My brother continues to play a significant role in caring for me even today. Over the years, my ongoing health challenges have required constant attention, coordination, and emotional presence from him. Inevitably, this has affected his personal life and career choices.

My mother has cared for me with extraordinary dedication throughout my life, and continues to do so now as I live with **pulmonary arterial hypertension (PAH)**. While her care has been a

source of strength, it has also been a source of emotional conflict for me — the awareness that my illness reshapes the lives of those who love me.

Although my family has never made me feel like a burden, I often carry an internal sense of guilt knowing that my condition has influenced their paths. This emotional weight is rarely discussed, yet it is common among people living with chronic heart disease — the feeling that the illness extends beyond our own bodies and into the lives of our caregivers.

Acknowledging this does not diminish the love behind their support. It highlights the need for **family-centered care**, emotional support, and honest conversations for both patients and caregivers.

CHD Does Not Always End with Surgery

My VSD was closed, but my journey with heart disease did not end there. Years later, I developed pulmonary hypertension, a condition that many patients and families are not adequately warned about.

Congenital heart disease is often viewed as something that can be “fixed” surgically. In reality, for many of us, it is a lifelong condition with evolving consequences — physical, emotional, and psychological.

Long-term monitoring, awareness, and follow-up are essential, even after successful repair.

Why Sharing These Stories Matters

CHD and pulmonary hypertension affect far more than the heart. They shape:

- confidence
- social development
- family dynamics
- mental health
- identity and self-worth

These effects are subtle, cumulative, and often invisible.

By sharing stories like mine, I hope we can broaden the conversation beyond surgeries, medications, and survival statistics. We must also acknowledge the human experience of living with congenital heart disease — the adaptations, the losses, the resilience, and the emotional cost.

Awareness, early monitoring, emotional support, and compassion matter, not just for survival, but for quality of life.

How I Deal with Uncertainties

Mr. Siddhant Rathi

CHD Warrior

Indore, Madhya Pradesh

“Tell me three months, I’d spend time with family. Tell me one year, I’d write a book. Give me ten years, I’d get back to treating diseases.”

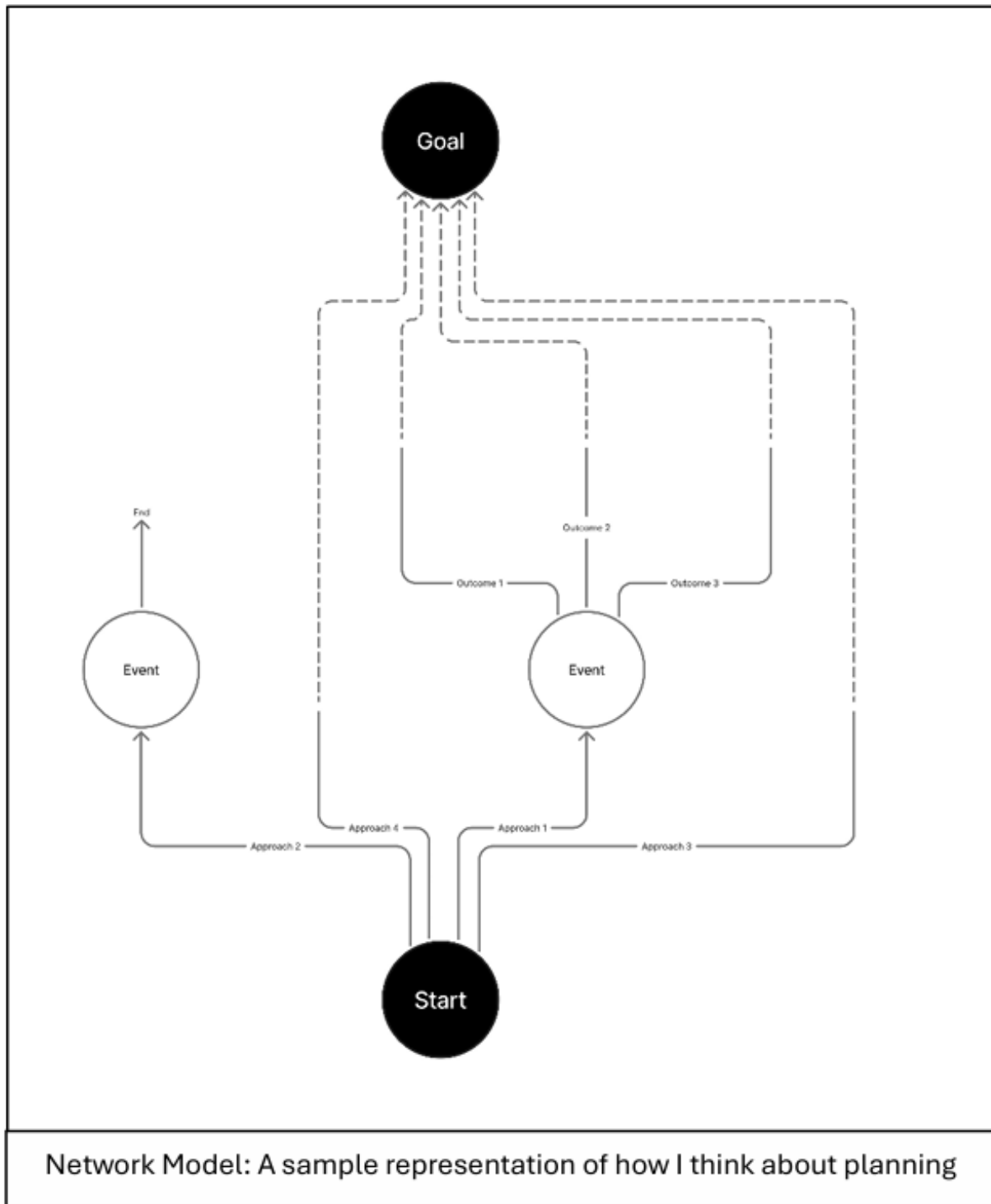
- Paul Kalanithi, When Breath Becomes Air

Dealing with uncertainty has been a bigger and bigger part of my life as I’ve grown older. There are short-term uncertainties like having bad days, falling sick, hospitalizations, or the number of things that might not go according to plan, as well as long-term uncertainties on career path, lifespan, and ambitions.

I’ve always been keen about planning, about optimizing things according to my parameters and adapting the plans to changes. However, growing older, I’ve found that this planning paradigm, which considers a plan as a concrete monolith with only a few adjustable variables, might be fundamentally flawed. To deal with a diverse number of uncertainties, the ‘plan’ also needs to be that much more flexible.

In common parlance, people often refer to a ‘Plan B’, a backup plan if the original one doesn’t work out. However, I’ve found that with the amount of uncertainty we deal with, just a plan B is not enough. So, I have a plan C, plan D..., and so on. But they are not complete plans, either.

The way I think of it is like a tree, with a number of branches going up. Each branch is a viable path/approach you can take, but it’s not a complete path, and you don’t know if that path will bear fruit at the end. These branches further have ‘events’ that have uncertain outcomes at the beginning, and when these events resolve/happen, depending on the outcome, the branch might again split into different branches/approaches of its own, or end. So, you start out with a number of branches and unresolved events, walk along many or all of the branches at the same time, adapt to events,



and hopefully, finally reach your outcome. In any case, with this approach, you are not just ‘planning’ but creating a network of paths and possibilities leading to your goal, and pursuing them will at least help you understand your goal and the landscape better, and in the process bring you at least a bit closer to it.

A fundamental part of this planning resiliency is being dynamic and flexible as events resolve, and to do so one needs to have an idea of the possible outcomes and an estimate of how likely each outcome is. The latter part is the hardest, and a lot of it is often learned by experience when plans don’t go as expected and events have unexpected outcomes, and all this helps a person ground themselves to reality and think from a realist perspective. It also encourages one to learn more and more about the world and their life situation, as it helps them better estimate the possibilities and prepare for the outcomes of these uncertain events.

This network model of planning has served me well, has enabled me to progress from life situations where I believed there’s nothing I can do anymore, and along with intentionality, has helped me to improve my life situations a lot. It works great still, and we can always adapt it if it doesn’t in the future :)

Journey of Faith



Ms. Riza Fatima

CHD & transplant warrior

Lucknow, Uttar Pradesh

In a quiet corner of Lucknow once lived a cheerful little girl whose laughter filled her home with joy. As the firstborn in her family, she was the heart of the household a bright, playful, and full of life. But when she was barely three, life changed in ways no one could have imagined.

One ordinary afternoon, while she was playing, she suddenly collapsed. Her tiny body turned cold, her heart Palpitations reached 250-300, and panic swept through her home. She was rushed to the hospital, where doctors delivered a diagnosis that shattered her parents' world: congenital heart disease (CHD) and atrial septal defect (ASD). Doctors spoke in words no parent ever wants to hear.

Her childhood, once carefree, now stood shadowed by surgeries, medications, and constant hospital visits. Doctors had informed her parents early on that heart surgery was the only remaining option for their daughter. Yet the decision was filled with fear; she was their first child, their cherished blessing, and the thought of losing her on the operating table was unbearable. Because of this fear, her early childhood surgery, planned when she was just three years old, could not be carried out.

As the years passed, life became a journey of constant panic and uncertainty. She would experience sudden episodes of rapid palpitations attacks that could strike anywhere, at any time. Her childhood, instead of being carefree, became a struggle against an invisible enemy inside her own body. Doctors spoke in words no parent ever wants to hear. Her tiny heart was fighting for survival. Surgeries loomed, medicines filled the house, and fear became her parents' silent companion.

Still, she grew up with a smile, a little girl who understood pain far too early.

Days turned into years, and she continued to live with the weight of this condition until one day, everything changed. She suffered a severe ASD attack, one that shook her family deeply. It was at that moment that her parents realized they could no longer wait. With trembling hearts but renewed determination, they decided to take her to Delhi for advanced medical care. It marked the beginning of a new chapter, one guided by courage, desperation, and hope for the life of their daughter.

This time, the doctors discovered something even more frightening: pulmonary arterial hypertension (PAH). A disease that slowly steals a person's ability to breathe. Her world and her parents' world collapsed. The doctors explained with helplessness that her condition had progressed beyond what they could control. Surgery was no longer an option; attempting it would mean risking her life. She was only twelve, yet old enough to understand every painful truth being spoken about her future. Still, she listened with courage, absorbing the weight of her diagnosis even as her heart trembled with fear. But no doctor could measure the size of her faith.

Her parents, shattered but determined, refused to give up. Clinging to whatever hope remained, they took her to Bangalore, praying that the doctors there might offer a miracle. Upon reaching the hospital, the doctors assured them that they would try their very best. For the first time in a long while, a faint spark of hope lit up their hearts.

Her surgery was planned. The day arrived. Holding her aunt's hand tightly, she walked toward the Operation theatre. Terrified and trembling, yet brave because she had no other choice. Tears slipped from her eyes - tears of fear, uncertainty, and the silent question every child wishes they never have to ask: "Will I come back?"

Before the surgery, the doctors performed an echocardiogram. What they saw shattered every hope they had built. Her PAH had become dangerously severe. Performing the surgery would mean that she might never return to her parents. With heavy hearts, the doctors cancelled the surgery.

Silence fell over her family like a storm. Every hope dissolved. Every prayer felt unanswered. All they could now do was hold on.

The doctors prescribed medication to manage her PAH and advised annual follow-ups in Bangalore. And so began a new chapter in her life, a life of check-ups, tests, and endless medicines. Every year, she returned to Bangalore, hoping something would change. The doctors tried everything: new treatments, stronger medicines, every option available. But the PAH remained stubborn, unyielding, refusing to improve. Yet through all this, she continued to move forward with courage, with strength, and with a heart that still believed in miracles.

Her teenage life was a silent war, not filled with school trips, friends, and carefree moments. Instead, she battled: oxygen dependency, severe breathlessness, endless injections, monthly hospital visits, constant pain in her chest, fear of severe palpitation.

Her teenage years were a battleground of breathlessness, weakness, and long school and college corridors. She completed her schooling, fighting severe symptoms. Still, she refused to give up her education and dreams. She completed her Bachelor's and later her Postgraduate degree while taking oxygen support, often gasping for breath between lectures. Life was anything but normal but her determination was extraordinary.

One day, returning from university, she suddenly tasted blood in her mouth. Moments later, she was vomiting blood, terrifying red streams she couldn't control. People around her panicked; her mother froze in shock. That was her first hemoptysis. *The first blood... and then the worst.* After that incident, life changed drastically. Every morning, she woke up scared: "Will I cough blood again today?"

Doctors explained her condition: her lungs were damaged, and bleeding could start at any time. That was only the beginning. Soon, she suffered repeated episodes: sudden torrents of blood, breathlessness so severe she couldn't whisper, dizziness, fainting spells, unbearable chest pain. Her mother watched helplessly as her daughter's life slipped between her fingers.

Then came the night the world nearly ended. It was a massive hemoptysis - buckets of blood poured from her mouth and nose. She remained conscious, trapped between life and death, fully aware that she might not survive the night. Hospital after hospital refused to admit her. Finally, one doctor whispered the sentence that broke her parents completely: "*She has only a few days left.*" Her mother's scream still echoes in her memory. Now, a journey of life and death starts. Clinging to the last thread of hope, her parents took her to Bangalore, a city she had yearly visited for her follow ups. This time, the journey was not for consultation...it was a race for survival. In the hospital, she was put on 24/7 oxygen. Nurses rushed every time her blood pressure dropped. Her veins collapsed from too many injections. She was so weak she couldn't walk more than a few steps. And then the final blow arrived. Her heart and lungs had reached their last stage. Doctors said only a heart-lung transplant could save her. Her parents broke down. They were told: She had hardly a year to live, A donor might not come in time, the surgery was extremely risky, the expenses were massive, and she might not survive the operation. Still, they chose hope.

After eleven long months of unbearable pain, 24/7 oxygen support, two heart failures, and repeated terrifying episodes of hemoptysis, her world had shrunk to a hospital bed and constant suffering. Every breath was a battle. Every hour was borrowed time. And then, one evening, the call finally came, the call she had prayed for with every beat of her weakening heart.

The hospital informed her family that a donor organ had been found. Her transplant surgery was scheduled for the next morning. Most patients tremble at the thought of such a major operation, but not her. She was brave, a girl full of courage, hope, and an unbreakable desire to live. For the first time in months, she felt happiness bloom inside her. She laughed, she glowed, she spoke to her family on a video call with excitement sparkling in her eyes, telling them:

“My life is going to change now. I will be fine.” But life, once again, tested her in the cruellest way.

While she was still speaking on the call, she suddenly began coughing blood. The colour drained from her face as her pulse dropped, her body weakened, and consciousness slipped away. It was her third heart failure and the most severe hemoptysis of all. This episode was either going to be the last of her life... or the last before her new life began.

She was rushed to the first wing CCU, where only the most critical patients were treated. There was no hope left in anyone’s eyes. Someone whispered to her mother that if the bleeding didn’t stop, the doctors would not be able to perform the transplant in the morning. She had been in that hospital for nearly a year, loved by every nurse and doctor. They had seen her fight every single day. Now they, too, cried for her. No one knew what the next hour would bring.

But she... she did not break. She believed with a strength no one else had that God would answer her prayers. And from that moment, destiny began writing a new chapter for her. The entire night passed in chaos. The bleeding would not stop. Doctors tried everything humanly possible. Nothing worked.

Morning arrived. Her mother stepped away for a moment to offer the Fajr prayer, placing her daughter in God’s hands. During that time, the nurses took her to the operation theatre. She was conscious, yet she hadn’t seen her mother before the surgery. As the doors of the OT closed behind her... something miraculous happened. The bleeding stopped.

She looked at the doctors and whispered that she wanted to meet her mother. But it was too late, there was no time. The only thing they could allow was a phone call. Inside the OT, lying on the surgical table, she spoke to her mother for the last time before the operation. Her voice was soft, steady, full of faith:

“Don’t worry, Ammi. Allah is with me. I will come back. Please have breakfast and keep praying for me.”

These were her final words before the anesthesia embraced her and the doctors began the surgery that would decide whether she lived another day. It was a night between life and death and a

morning when miracles quietly began. Her body lay surrounded by tubes, pipes, IV lines, machines, and surgical lights. Doctors fought her death with unmatched skill and mercy. And then...A new heartbeat began inside her. A new breath entered her lungs. God had written a new chapter for her. When she woke up, two days later, she whispered: “Thank God... I survived.”

Waking up from anesthesia felt like returning from another world. She couldn’t speak. She couldn’t move. Her body hurt everywhere. Each breath felt stitched and raw. She cried silently at night; in pain, she couldn’t explain. She underwent multiple bronchoscopies, draining fluid from her lungs, endless injections, tubes in her throat and stomach, infections, sleepless nights, months of isolation, but she endured it all with patience. Her Family stayed beside her day and night, praying with every tear. But step by painful step, she rebuilt her life. She breathed without oxygen. She walked. She lived.

This article is not fiction. It is not a story heard from someone else. It is written by the girl who lived every breath of it, who fought battles that no child should ever face, who collapsed more times than she can count, who tasted blood instead of breath, and who survived because God chose to rewrite her destiny. This is the real-life journey. Today, I write this story myself with my own hands, my breath, my own heart. My life has changed in ways I once never imagined. I am alive. I am grateful. And above all...I am faithful. I would like to express my heartfelt gratitude to my doctors for the immense effort they put into my transplant journey. Their unwavering care, dedication, and compassion carried me through the most difficult moments of my life. It is because of their hard work and commitment that I have been given a second chance at life, and I will remain forever grateful. I also extend my deepest thanks to my donor for giving me the priceless gift of a new heart and lungs. Her generosity has allowed me to breathe, live, and dream again. I pray that her soul rests in eternal peace. What she has given me can never be measured in words.

Lastly, I want to thank my parents for their immeasurable love and support emotionally, physically, and financially. They stood by me through every fear, every pain, and every hope. Without their strength, I would not have reached where I am today. My parents gave everything they had, emotionally, physically, and financially, to keep me alive. Every heartbeat today belongs to them.

“Miracles still happen. Sometimes, they look like doctors. Sometimes, they look like family. And sometimes, they look like courage.” I write today not as a victim of illness but as a warrior who defeated it. This is my story. A story I lived, breathed, survived, and finally gathered the strength to write. Every word comes from my memories my pain, my fear, my courage, and above all, my faith in God. I write this today with the breath I once thought I’d never have. My story is not just

survival It is a testament to the power of courage, a parent's prayer, and God's mercy. I am a living proof that even the weakest breath can become the strongest roar of victory.

“If life feels unbearable today, hold on. Hard days are not the end; they are the beginning of miracles. Be patient with God's plans. Har Mushkil ke baad Asani Hai aur Allah Sabr Karne Walo ke Sath Hai. Agar aaj Zindagi me Kuch acha Nahi Ho Raha, Toh wo end Nahi... Picture Abhi Baqi Hai Mere Dost.”

From hospital bed to standing ovation: fulfilling a forbidden wish



Ms. Neha Kumari

CHD Warrior

Dhanbad, Jharkhand

It is winter, and I am writing this from the library of RIMS, the renowned medical college in Jharkhand. I am **Neha**, a second-year Bachelor of Dental Surgery student. My life before arriving here was a true rollercoaster, especially concerning my health. As a naturally curious child who chose to study science, this combination ultimately led me to discover my congenital heart disease (CHD).

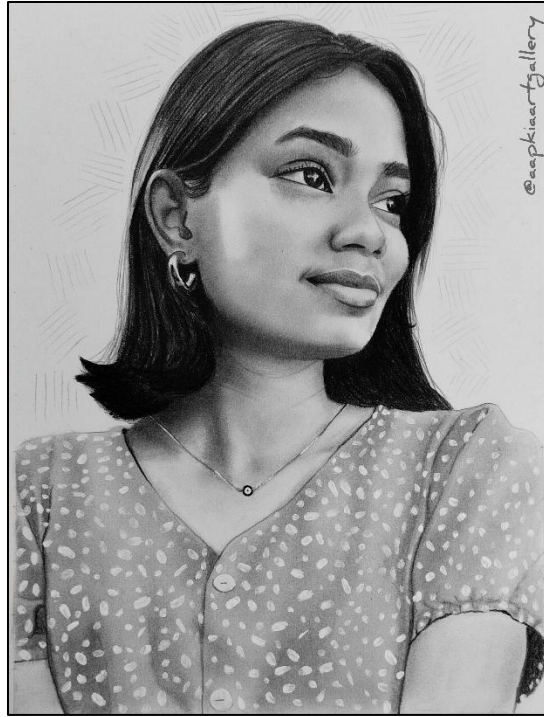
Growing up with CHD, I never truly understood what "normal health" felt like; the complexities within my body were simply my reality. I frequently experienced severe palpitations and often felt that "something was wrong" with my chest, though I couldn't put a finger on it.

It wasn't until the eleventh grade, having chosen biology, that the puzzle pieces clicked. A chapter in my textbook, "*Body Fluids and Circulation*," was taught in great detail. It was in that class that I diagnosed myself: "*It's not something wrong with my chest, it's something wrong with my heart.*"

My circumstances added another challenge. I lost my mother when I was seven and grew up without my father. My maternal grandparents raised me with boundless love. The very day I made this self-diagnosis, I explained everything to them. The next day, we met with Dr. A. K. P. Singh, a retired cardiologist in Jharkhand. He immediately confirmed my diagnosis and guided us to the Sri Sathya Sai Sanjeevani Hospital in Raipur.

There, I met Dr. Atul Prabhu sir, one of the kindest and most genuine people I have ever encountered. He performed two procedures: a PDA device closure in 2018 and an Ablation in 2019.

This felt like a rebirth, yet it wasn't all smooth sailing. The recovery from my second surgery deeply affected me, leading to a period of stage-two depression. Simultaneously preparing for the NEET examination, this mental health struggle drastically disrupted everything. For seven to eight months, I couldn't focus on my studies. Yet, I fought the depression by keeping myself completely busy doing "what I love."



Self-portrait done by Neha Kumari

I had been a good artist in school, but this eight-month period transformed me into a professional *artist*. I used free internet resources to learn everything basic, began uploading my work, and even started receiving commissioned requests.

Eventually, I cracked the *NEET exam*. Attempting a national-level competitive exam immediately after recovery and while on medication was incredibly challenging. Many times, I felt ready to give up, but my success was not just due to my hard work; it was equally a result of the unwavering mental support and love from my grandparents.

I always carried an unfulfilled dream: a wish to dance. Due to the severe palpitations, it was never possible. But today, I am finally fulfilling that wish! I adore classical dance, and in my last college competition, I was honored to win a *gold medal* with a standing ovation.

Though seven years have passed since my procedures, I can still vividly recall the continuous "beep-beep" of the monitor. Yet, that sound is now beautifully layered over by the constant,

reassuring support of my doctors, the joyful laughter of my fantastic friends, and the enormous, life-affirming love of my god send grandparents.

Life with CHD has never been easy, and it remains a challenge, but each day, I move forward with the hope of fulfilling my bucket list.

Taught me what

No one can limit you;

just let your soul live the best, till the last breath.



News Highlights

3/13/26, 8:32 AM

PM Modi meets 2,500 children who underwent free heart surgeries at Sri Sathya Sai Hospital - Times of India

Printed from

THE TIMES OF INDIA

PM Modi meets 2,500 children who underwent free heart surgeries at Sri Sathya Sai Hospital

TNN | Nov 1, 2025, 04:27 PM IST



RAIPUR: Prime Minister Narendra Modi on Saturday interacted with 2,500 children at the Sri Sathya Sai Sanjeevani Child Heart Hospital in Nava Raipur, during the hospital's special programme titled "Dil Ki Baat." These children had successfully undergone free cardiac surgeries under the hospital's "Gift of Life" initiative, an effort that has already changed the lives of more than 25,000 children across India and neighbouring countries.

Prime Minister spoke affectionately with the young patients and their families, asking about their health, studies, and dreams for the future. At one point, he was seen embracing a child, a spontaneous gesture that drew smiles and applause from the

audience.

Source: <https://timesofindia.indiatimes.com/city/raipur/pm-modi-meets-2500-children-who-underwent-free-heart-surgeries-at-sri-sathya-sai-hospital/articleshow/125014507.cms>

ISSN 0972 - 1568 (print) | ISSN 3048 - 653X (online)

INDIAN TRANSPLANT NEWSLETTER

Publication from MOHAN FOUNDATION

In the news – International

Australian Man Survives 100 Days with World's First Artificial Titanium Heart

Poonam Sharma, Sujatha Suriyamoorthi
MOHAN Foundation, India

In a significant advancement of life-support cardiac technology, an Australian patient has become the first human to survive 100 days with a titanium artificial heart.

Following a life-threatening heart failure, a 40-year-old patient underwent the BiVACOR Total Artificial Heart (TAH) implant at the St. Vincent's Hospital in Sydney in November 2024.

In this year February, he became the world's first patient to be discharged from the hospital with a functioning artificial heart. He subsequently resided at home with the device until the donor heart was acquired in the month of March'25. Following a successful transplant, he is now recovering nicely according to a joint statement from St. Vincent's Hospital, Monash University, and BiVACOR. Built to be robust and could be a long-term fix for patients with end-stage heart failure, the BiVACOR TAH,

made of titanium, has a single magnetically suspended rotor that replaces the two ventricles of the failing human heart.

With the five patients receiving the implant, The BiVACOR Total Artificial Heart has already undergone the initial testing through the U.S. FDA's Early Feasibility Study. July 2024 marked the first case when a 58-year-old man was kept alive at Texas Medical Center for 8 days until the availability of a donor heart.

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To cite : Sharma P, Suriyamoorthi S. Australian Man Survives 100 Days with World's First Artificial Titanium Heart. In the news. Indian Transplant Newsletter. 2025 Jan-Mar; 24(1):p2. DOI:10.64384/ITN.2025.003

Source: <https://www.itnnews.co.in/indian-transplant-newsletter/issue75/Australian-Man-Survives-100-Days-with-Worlds-First-Artificial-Titanium-Heart-1368.htm>

3/13/26, 8:59 PM

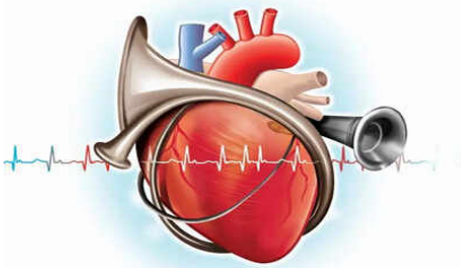
Registry of congenital heart diseases for early detection - Times of India

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THE TIMES OF INDIA

Registry of congenital heart diseases for early detection

Jan 26, 2026, 07:00 AM IST



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.

Source: <https://timesofindia.indiatimes.com/city/jaipur/registry-of-congenital-heart-diseases-for-early-detection/articleshowprint/127498956.cms?val=3728>

Innovations in Congenital Heart Surgery: From 3D Models to Virtual Reality



In his work, **Dr. Mahesh Kappanayil** demonstrates how emerging technologies such as 3D printing and virtual reality can transform the management of complex congenital heart defects. A major breakthrough in his work occurred when he created a **life-size 3D-printed model of a 17-year-old patient's heart** to visualize a highly complex defect. The model enabled surgeons to plan and perform a surgery that had previously been considered impossible, marking the **first 3D print-assisted cardiac surgery in South Asia**. This experience led him to establish a dedicated medical 3D printing lab at Amrita Institute of Medical Sciences, where patient-specific models are used to plan surgeries for rare and complex conditions.

Building on this foundation, his team later incorporated virtual reality, allowing clinicians from different countries to collaborate in immersive digital environments and analyze holographic models of patients' hearts. His work illustrates how integrating technologies such as **AR, VR, and AI** into clinical practice can improve surgical planning, enhance collaboration, and expand treatment possibilities for patients with previously inoperable conditions.

Source: <https://www.youtube.com/watch?v=j-d8-RVOCJE>

WEBINARS

Our community members engage with families through different individual Facebook pages and support groups, including Justice for Heart Warriors, Hope, Congenital Heart Defect Awareness Campaign, and Congenital Heart Disease India. Through these platforms, we regularly organize webinars and interactive sessions with renowned paediatric cardiologists and paediatric cardiac surgeons from different hospitals across India. We also share health-related educational videos to promote awareness about congenital heart disease.

Note: The following is a list of webinars and sessions conducted since the last issue of Hriday Gatha.



GLOBAL CHD ALLIANCE

CPR TRAINING SESSION FOR EVERY PARENT, EVERY HEART

This free CPR webinar is specially designed for parents of children with Congenital Heart Disease (CHD), but open to anyone eager to learn life-saving skills.

Dr. Atul Prabhu - Speaker
Pediatric Cardiologist
championing early diagnosis and accessible cardiac care.

Scan the QR Code to join the Zoom session
27th July Sunday
7:00 PM to 8:00 PM

Follow Global CHD alliance



Q&A Session for CHD Patient Families

With Pediatric Cardiology Experts

Are you a patient or caregiver of a child with congenital heart disease (CHD)?
Do you have questions, worries, or confusion about the care, treatment options, or future?
Join us for a one-hour interactive session designed to answer your concerns and bring clarity.

Join us on
13th August 2025 (Wednesday)
7.30Pm onwards

Special Keynote on World Organ Donation Day
Speaker: Dr. Swati Garekar - Senior Pediatric Cardiologist
Topic: Organ Donation and Transplantation

Live Q&A With Our Expert Panel:

Dr. Swati Garekar
Fortis Hospital, Mumbai

Dr. Amitabha Chattopadhyay
Narayana Superspecialty Hospital, Andul

Dr. Soumyaranjan Das
Fortis Escorts Heart Institute, New Delhi

For queries whatsapp us at:
9831870041
9101523700

Organised by:



QnA Session for CHDs

13th webinar from Justice For Heart Warriors

An exclusive question and answer session for the patients, parents and the caregivers.

The esteemed panelist

Dr. Atul Prabhu
MD, FNB Cardiology

Sonam Manoj
Licensed Clinical Psychologist (BCI)
Senior Research Scientist (ICMR)

Key Expertise:
1. Pediatric Cardiology and Special Needs Interventions
2. Neurodevelopmental Outcomes in Children with Congenital heart Conditions
3. Life Skills and Wellness Curriculum Development
4. Senior Research Scientist leading cohort studies in pediatric neurodevelopment.

An Online Webinar through Zoom meeting.
Time - 7:00 PM, 1st November 2025 (Saturday)

Organised by



Virtual Session YOGA CLASS

Yoga session for the CHD community - parents, grandparents, siblings...all may join

JOIN SESSION:
7th February (Saturday)
7 am - 8 am



FINANCIAL PLANNING & MEDICAL CROWDFUNDING

for families affected by congenital heart defect

14th Webinar from Justice for Heart Warriors

12 FEBRUARY 2026
7.30 PM - 9.00 PM Online on Zoom

7.30 PM
MR. JITENDRA P. S. SOLANKI
• SEBI Registered Investment Adviser
• Financial & Estate Planning Expert
• Author & National Resource Person (NISM-SEBI)

8.30 PM
MR. PRASHANT PANDEY
• Vice President - Patient Operations at Impactguru.com
• 10+ Years Experience in Medical Crowdfunding
• Expert in Campaign Strategy & Fundraising Support

REGISTER NOW WhatsApp your name and webinar topic to 9831870041 8806174444



GLOBAL CHD ALLIANCE

DIET & EXERCISE for CHD Patients

A Guide for Parents

Speaker 1
Dr. Suparna Mukherjee
PhD Scholar (Dietetics), RD
Executive Committee Member, INCD, Nutrition Society of India

Speaker 2
Dr. Greshma Shenoy (PT)
BPh, MS, Cardiac Rehabilitation & Heart Failure expert

Moderator
Dr. Atul Prabhu
MD, FNB
Pediatric Cardiologist & Electrophysiologist

Friday, 13 Feb 2026 | 7 PM

WEBINAR

REGISTER NOW

Justice for Heart Warriors at PCSI 2025: Bringing Patient Voices to the National Stage

CHD ALLIANCE OF INDIA

PCSI 2025

Beyond the Surgery

Bridging Policy and Practice in CHD Care – Voices from the Ground

HALL E
20th SEPT 2025 | TIME: 1:00 PM - 2:00 PM

 Dr. R. Krishna Kumar Panelist	 Dr. Omprakash Shete Panelist	 Dr. Debasis Das Panelist	 Dr. P. Rajashekar Panelist
 Ms. Bistra Zheleva Panelist	 Mr. Siddhant Rath Panelist	 Ms. Manjushree Y. Chavan Panelist	 Dr. Anita Saxena Moderator

A Luncheon Symposium bringing together families, clinicians and policymakers

EVENT PARTNERS
JG, Global ARCH, Children's HeartLink

FINANCIAL PARTNER
Children's HeartLink INDIA FOUNDATION



Acknowledgements:

There were a lot of people and organizations who supported us and made it possible for us to be there. We are grateful to:

- Our sponsors
- CHD Alliance of India
- Children's Heartlink India Foundation
- Global Alliance for Rheumatic and Congenital Hearts
- Pediatric Cardiac Society of India