Heart Children

WE'RE WITH YOU THROUGH YOUR JOURNEY

Strategic Priorities 2025–27

COMPANY NO: 371707. REGISTERED CHARITY NO: 10022. CRA: 20025274

OUR MISSION

TO ADVOCATE FOR, AND PROMOTE THE WELLBEING OF, PEOPLE BORN WITH CHD AND THEIR FAMILIES FROM THE EARLIEST POINT OF PRE-NATAL DIAGNOSIS AND THROUGHOUT THE PERSON'S LIFETIME.

Izzy Lonergan, Tipperary, Lillian Keane, Wexford
& Faye Turner, Tipperary, at the
Heart Children Summer Camp 2024

Heart Children Youth Council members, (l to r) Amy Poynton & Sínead Burke with broadcaster, Ray D'Arcy, at the Hearts and Stars Charity Ball,2024

Introduction

Congenital Heart Disease (CHD) is a condition that results when a baby's heart does not develop correctly during pregnancy. The resulting structural abnormalities of the organ at birth have a detrimental effect on the flow of blood in the body and there is a high likelihood that surgical intervention will be required to sustain life.

There are over 40 different types of structural abnormalities, all with stand-alone names, but which are referred to generally as 'congenital heart disease'. Some children will be born with just one of these while others will be born with several, and no two children will have the same set of conditions or symptoms.

In Ireland, 500-600 babies are born with CHD each year. This figure is almost three times greater than the number of childhood cancers diagnosed annually. Yet despite the relatively high incidence of CHD globally - one in every 100 births worldwide - there is still low public awareness and understanding of congenital heart disease.

OUR VISION

TO SUPPORT PEOPLE WITH CHD TO LIVE CONFIDENTLY, STAY WELL AND LIVE LIFE TO IT'S FULLEST.

Cian Conway, Waterford, at the
Heart Children Summer Camp 2024

Who we are

Here in Ireland, we are fortunate to have access to world-class paediatric cardiology services which deliver individualised medical care to every child with CHD. 97% of all children born with the condition now survive into adulthood. Today, more people than ever are living with CHD in our communities; attending our schools and colleges; taking up places in the workforce and building bright futures.

Yet while so much is possible medically, our healthcare system falls short in providing a rounded, holistic programme of care that balances the mental and physical health of people with CHD and their families.

Heart Children was set up to build a community for people living with and caring for a loved one with CHD. We work to provide some of the much-needed services that prepare people with CHD to cope with medical trauma and help parents and siblings adapt to the inevitable changes that result when there is someone with a lifelong cardiac condition in the family. We do what we can with limited resources to provide the care that families and adults with CHD need to thrive.

Heart Children Youth Council members, (l to r) Ailbhe Canavan, Galway, Gemma de Burca and Sínead Burke, Dublin, with Amy Poynton, Wicklow, volunteering at the Summer Picnic 2024

Our Services

T: 01 874 0990
E: info@heartchildren.ie

2 x full-time staff

1,500 + members

Psychological Support – €18,670

6 sessions with a Snr Clinical Psychologist who provides support via phone or online to members countrywide. This is an on-demand service accessed by contacting Heart Children directly. Further support offered through online videos; group webinars and workshops.

In 2024 we provided psychological support for 30 members.

Financial Aid – €33,000

Grants to parents of children with CHD who are hospitalised long-term or who need to travel abroad for heart transplant or other treatments not available in Ireland. Applications accepted from Social Work Dept in CHI Crumlin only.

In 2024 we provided grants to 85 families

Home Testing Meters – €4,195

We fund home-testing meters that allow people with CHD on warfarin medication to monitor INR levels from home. Requests come from the CNS team in CHI Crumlin and the Adult CHD Unit in the Mater Hospital.

In 2024 we provided grants to 8 meters to members

Play Therapy – €18,380

14 play therapy sessions for children with CHD and their siblings (aged 4-12) close to home. Provided by independent, accredited play therapists nationwide.

This is an on-demand service accessed by contacting Heart Children directly.

In 2024 we provided play therapy support to 25 children

Adolescent Support – €8,500

Two day residential summer camp for adolescents with CHD in Connemara, organised social events and annual conference.

In 2024 we organised our first camp for adolescents with CHD.

Family Events – €16,000

Fun for all the family providing good times, lifelong memories and community building opportunities.

“I am proud of how far I have come”.

“Live in the moment.”

“My challenges help me grow.”

“The story of life has many chapters. One bad chapter does not mean it is the end of the book.”

“You can be what you want to be.”.

“A bad day doesn’t equal a bad life.”

“Own your condition, don’t let it own you.”

“No such thing as can’t.”

✱ Positive affirmations provided by adults with CHD and parents of people with CHD who attended the Beat Goes On Conference 2024

Strategic Priorities 2025-2027

1. SUPPORT

Consolidate our successes and develop the reach and depth of our services

- Support for new/other audiences in the member profile
- Provide information via podcasts, videos info sheets, pack on charity.
- Establish Family Support Worker role

2. CAPACITY

Grow capacity

Increase:

- Income
- Staffing
- Membership
- Volunteering

3. ADVOCATE

Lobby for improved services for the adult CHD population

- Set-up committee on adult services
- Develop action plan
- Partner with the Heart Foundation:
- Set out case to Dept of Health/ HSE / REOs

4. COMMUNITY

Continue to build and strengthen Ireland's CHD community

Establish:

- Pre-natal meet ups
- Coffee mornings in Crumlin
- Social events for teens / Youth Council activities
- Workshops for adults
- Services for older people with CHD


Heart
Children

Priority 1. Support

Family Support Worker

Establish and recruit for this strategic support role which will allow Heart Children to support families and provide access to the organisation's services from the outset.

Expand and Develop Services

- Family Support Worker role in CHI Crumlin
- Supports for those who receive pre-natal diagnosis
- Regional supports for PECs through HSE funding
- Annual monthly webinar series; podcast for adults
- In-person workshops for adults

Information

- Greater range of information resources available to people at all stages of their life journey with CHD.

Priority 2. Capacity

Income

Pursue new opportunities for support from
- Corporate sector
- HSE

Develop proposal and costing for major fundraising campaign

Staffing

Establish Family Support Worker role as three year pilot
Expand employment possibilities with
- CE Scheme
- Other resourcing

Volunteers

Further embed the culture of volunteering from the membership and look at other avenues.

Priority 3. Advocate

Board Committee

Design clear pathways to advocate for more staffing and support for the Adult CHD Unit in the Mater Hospital

Establish a working committee within the Heart Children board to action and progress these pathways.

Undertake a piece of research to evaluate current services with a view to highlighting the shortcomings.

HSE

Open discussion with the Dept of health and the HSE about the need for improved ACHD services.

Call for improvements through media campaign and lobbying.

Priority 4. Community

Develop Connectivity

More in-person meet-ups / pre-natal parents / new parents / coffee mornings in CHI Crumlin / young teenager social events

Build Supports/Activities at Local Level

Respond to membership call for services close to home in communities throughout Ireland.

Supports for Adults

With a growing population of adults living with CHD, create specific services for the various age groups to include those living into later life.

What is a congenital heart disease/defect?

- Congenital heart disease arises when a baby's heart does not develop correctly during pregnancy. In results in problems or defects with the heart's structure that affect the flow of blood through the body.
- Common problems include holes in the heart walls and narrowed or leaky valves. In more complex forms, blood vessels and/or heart chambers may be missing, poorly formed, or in the wrong place.

How common is congenital heart disease?

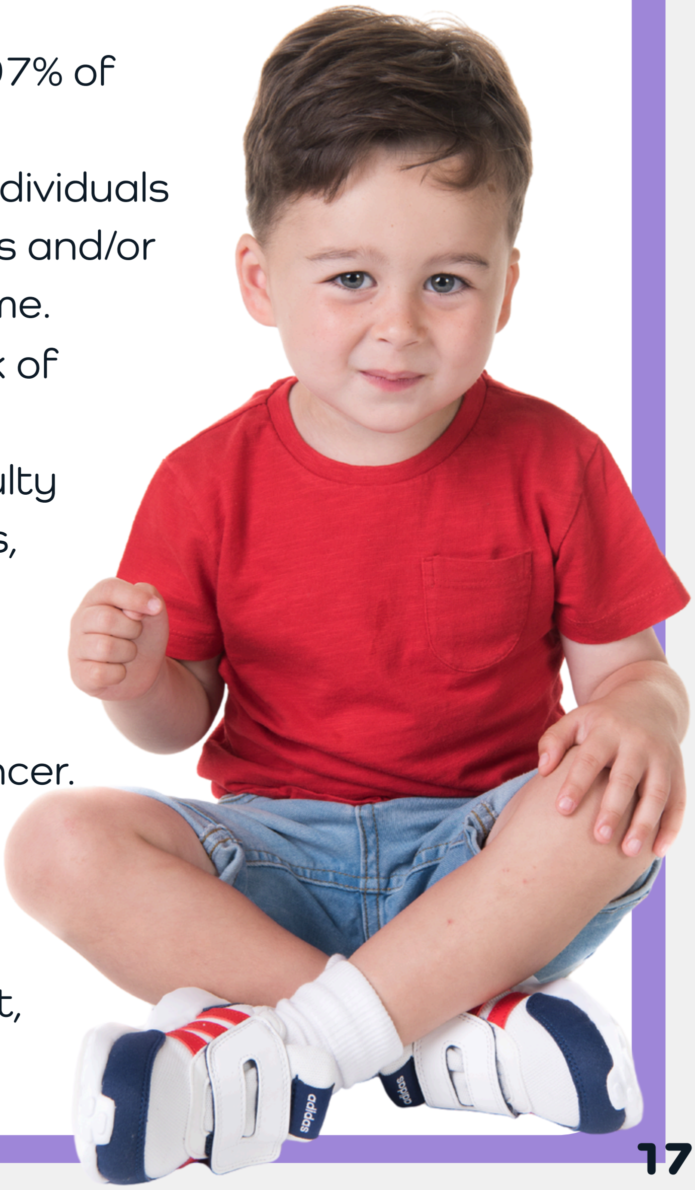
- CHD is the most common birth defect worldwide.
- 500-600 infants are born with CHD in Ireland each year.
- CHD occurs in one in every 100 births.
- It is estimated that approx. 20,000 people are living with CHD in Ireland.

What causes congenital heart disease?

- Most causes of CHD are unknown.
- Only 15-20% of all cases are related to known genetic conditions. Most are thought to be caused by a combination of genes and risk factors such as maternal diet and certain chemicals and medications.
- Maternal diabetes is a recognised cause of CHD. Maternal obesity, smoking, and some infections may also increase the risk of having a child with the condition.
- A baby's risk of having a CHD is increased three fold if the mother, father, or sibling has CHD.

What is the lifelong impact of congenital heart disease?

- Approx. 25% of children born with CHD will need heart surgery or other interventions to sustain life.
- Thanks to surgical advances, over 97% of children now live to adulthood.
- Surgery is often not a cure. Many individuals with CHD require multiple operations and/or interventions throughout their lifetime.
- People with CHD face a life-long risk of health issues such as: growth and eating, developmental delays, difficulty with exercise, heart rhythm problems, heart failure, sudden cardiac arrest, stroke, breathing problems, kidney failure, seizures, mental health challenges, and increased risk of cancer.
- Having CHD can result in lifelong neurodevelopmental and neurocognitive effects, leading to challenges in education, employment, and social relationships.



The future for Heart Children

It is estimated that there are up to 20,000 people living with congenital heart disease in Ireland. Thanks to medical advances, 97% of those born with CHD are now living to adulthood. Heart Children is committed to ensuring support for people with CHD and their families throughout their lifetime.

In the course of the next three years we will be working to support families who receive a diagnosis at the 20 week pre-natal scan, providing more regional activities and workshops, and building a stronger community for older members whose 're-modelled hearts' are now taking them into later life and even into retirement.

The biggest gain for Heart Children and for heart families will be the creation of a Family Support Worker role in the Children's Heart Centre at CHI Crumlin. The role will support families on their CHD journey and introduce Heart Children's services from the very beginning.

The strategic priorities outlined in this document will be managed across the three years of the plan. Progress will be monitored by the CEO and board bi-annually to ensure we remain on track for success.

Heart Children will continue to build a strong community for Ireland's CHD population and to advocate for improved integrated care for our members.

Sheila Campbell, CEO,
Heart Children.

Heart Children Board Members at the Hearts & Stars Charity Ball, Oct 2024, with special guest, An Taoiseach, Simon Harris.

(L to R) Rachel Power, Lisa McAlister, Michael Teehan, John McGuckian, Veronica Yeomans, Sheila Campbell (CEO), Simon Harris, Pearse Corcoran, Denis O'Connor.

Claire Adams
Pearse Corcoran
Dympna Donnelly
Lisa McAlister
John McGuckian

Denis O'Connor
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