CHILDREN'S HEARTBEAT TRUST

Northern Ireland's
Children's Heart Charity

Charity no: NIC 102410

1ST APRIL 2023 – 31ST MARCH 2024

Annual Impact Report

Welcome Messages

Chair's Message

I am thrilled to present the 2023/24 Impact Report from Children's Heartbeat Trust.

This year has been transformative for our charity, having welcomed Joanne McCallister as our new CEO.

In collaboration with our heart families and children, healthcare professionals and volunteers, donors and fundraisers, and other stakeholders, our dedicated team set the vision for our future, as presented in our ambitious 2023-2027 strategy.

At the heart of this strategy lies the voice of our young people and their families. By gathering their insights, and feedback we are co-designing new support services and enhancing existing ones.

A shining example of this is our Children's Ambulance, which completed over 200 journeys in its first year!

As we prepare to celebrate our 40th anniversary in 2024, we have a unique opportunity to reflect on the growth of our support services over the last four decades.

This milestone also compels us to look forward, addressing the evolving needs of our heart families and finding innovative ways to address these.

I am continually grateful for the unwavering commitment of our voluntary Board of Directors. Their expertise and dedication are vital in guiding the charity's growth with integrity, accountability, and transparency.

I hope these selected highlights of our work inspire you, as much as they inspire us.

Professor Nichola Rooney, Chairperson

CEO's Message

This past year has been an exciting one for Children's Heartbeat Trust. We have provided more financial support than ever before against the backdrop of the cost of living crisis; strengthened our research and policy work and created STARS, our new programme for bereaved parents.

None of this would have been possible without the drive of our amazing team, a truly tireless effort compassionately delivering vital services, fiercely advocating, creatively fundraising, all whilst researching and developing new models of support.

I also want to acknowledge our special group of trusted parental volunteers who run our Family Support Groups; they consistently provide much needed emotional and practical support – alongside a lot of fun- to other heart families across NI.

Finally, a word of thanks to our donors. Our support services would be unable to continue without the generosity of local businesses, schools, clubs, Trusts and especially our own heart families giving back. We are so grateful to everyone who has undertaken fundraising for us this year, provided a grant, or made a donation, no matter the size.

With your continued support, we will be able to grow our services for those families who need us now and in the future.

Enjoy reading!

Joanne McCallister,
Chief Executive

Family Support


Abigail (4)

29 parents trained in Infant Massage.

58 antenatal families supported through pregnancy.

119 families used our parent accommodation in Royal Belfast Hospital for Sick Children.

"Children's Heartbeat Trust helped us in our little family's darkest and unknown period; being able to stay in parents' accommodation in the Royal to simply wash, eat and take a step away from the ward to recharge made this dark time so much brighter."
Heart Parent

319 heart families received bedside emotional support on the hospital ward.

"There are no words to explain the complete support you would get from Children's Heartbeat Trust, especially whilst in hospital. They go over and beyond anything we could ever imagine. The CHT Team do amazingly well at checking in, visiting us in hospital and offering emotional support. I feel that I can approach them so easily and they respond instantly. Having that safety net positively impacted our mental health."
Heart Parent

Family Support

24 bereaved families supported through our CHT STARS programme.

"Thank you for not forgetting us. It really means the world. We lost so much when our daughter died so it has been such a support gaining new friends who understand what it means to live through such a tragic loss. We felt so alone in the months that followed and still haven't heard a word from some of our friends, I guess they don't know what to say. Learning that we are not alone, and this is normal for parents in our position has been a comfort."
Heart Parent

502 people enjoyed our seasonal Family Fun Days

"CHT always give amazing family days for our heart warriors and opportunities for parents to support each other. These events are very important. Siblings really enjoy them, and an event is something to really look forward to and remember."
Heart Parent

The Kane Family

£110,400 in financial support provided to 216 families travelling for cardiac care or facing long term hospital admissions.

83 families benefitted from a short break at one of our respite caravan stays.

Hospital Support

WE PROVIDED THE HEART CENTRE AT THE ROYAL BELFAST HOSPITAL FOR SICK CHILDREN WITH:

9 portable SATS monitors allowing families to monitor their child’s oxygen saturation levels at home so the clinical nurse specialist team can access accurate information without the family having to travel to a hospital appointment.

10 CoaguChek machines empowering parents and young people to safely manage warfarin levels at home reducing the incidences of complications and hospital visits.

Youth Support

11 young people and their caregivers attended Transition Day, to support the transition from childrens to adult cardiac services.

16 young people took part in our Summer Blast residential to improve their mental health and build their peer support network.

One of these young people who took part was Hope (17).

Hope was born with a heart condition which means only half of her heart works. However, this hasn't stopped her from leading a full life. She is beginning her final year of school with hopes of going onto further education and is very much looking forward to the next Summer Blast!

Hope:

"I want to be an advocate for young people to show them there's a positive future with congenital heart disease."

Our Support Groups

Our parent-led Heart Family Groups are a lovely introduction to the charity and other local heart families. These groups operate all over Northern Ireland and are open to the whole family. They are best described as mini family fun days! Families tell us they can sometimes feel isolated once they have received their child's diagnosis and although you might feel like you are going through this alone, we promise you aren't – even though it may feel that way sometimes.

Without our group organisers, we simply couldn't run our local Heart Family Groups so we are so grateful this team of lovely heart parents dedicate their time, energy and kindness to helping us support other local heart families. They are always thinking outside of the box and doing all they can to ensure each member of the family has a fun day out whilst being on hand to point them in the right direction for further support or providing a safe space for parents to share their story. A massive heartfelt thank you to all of our brilliant group organisers and the amazing work you do!

Hear from our Belfast Group Organiser Jean who shares her experience as a volunteer:

CLICK HERE SCAN HERE

10 local Support Groups across NI.

162 families supported through our Support Groups.

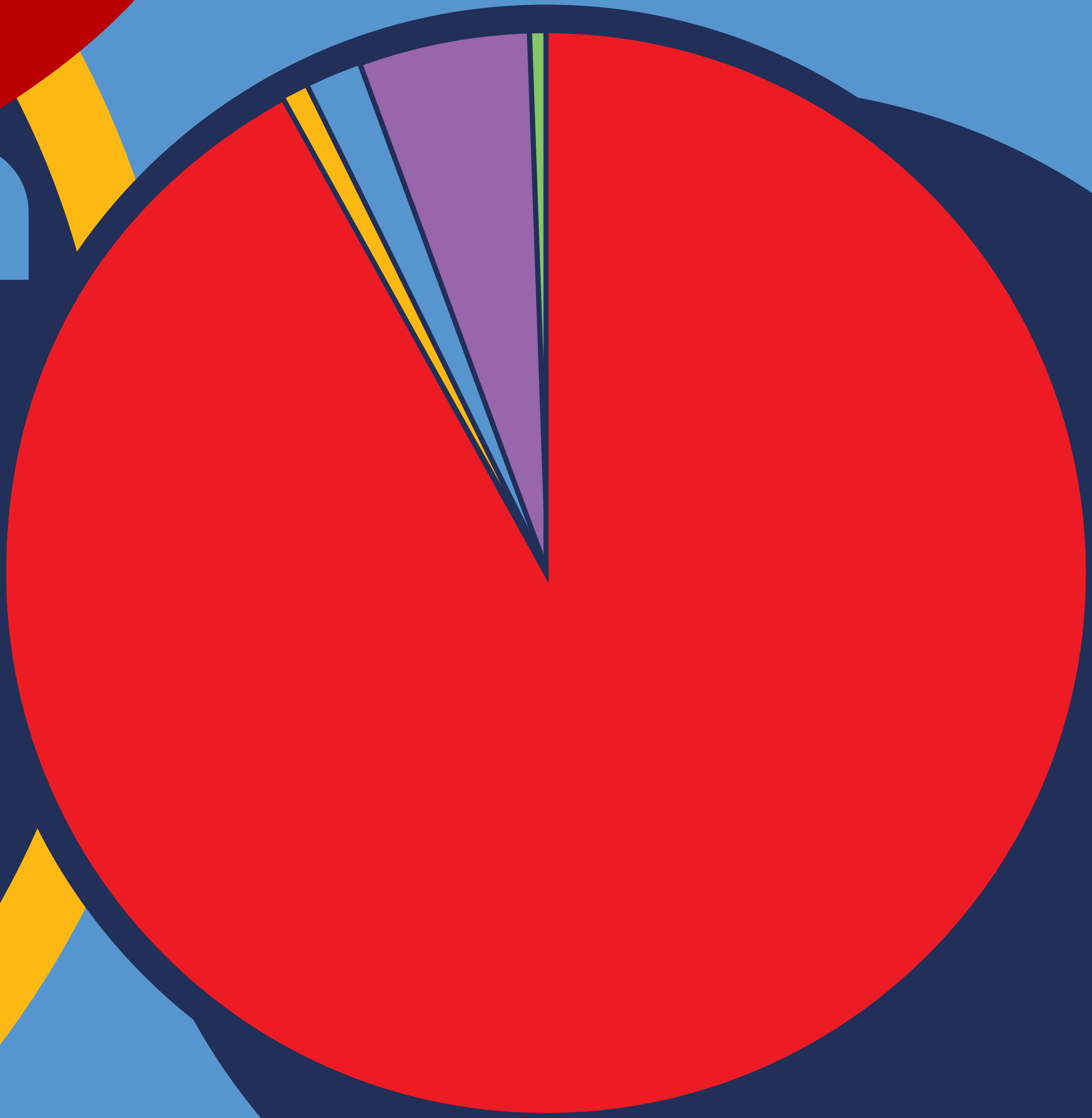
"I soon came to realise that I wasn't alone and in fact I was so lucky to have such great support from our local family support group." Heart Parent

Revenue

Financial Performance

INCOME

🔴 Donations and legacies: 92.20%
🟡 Charitable activities: 0.66%
🔵 Investments: 1.85%
🟣 Gains from investments: 4.85%
🟢 Other: 0.44%



Income Total:
£573,986

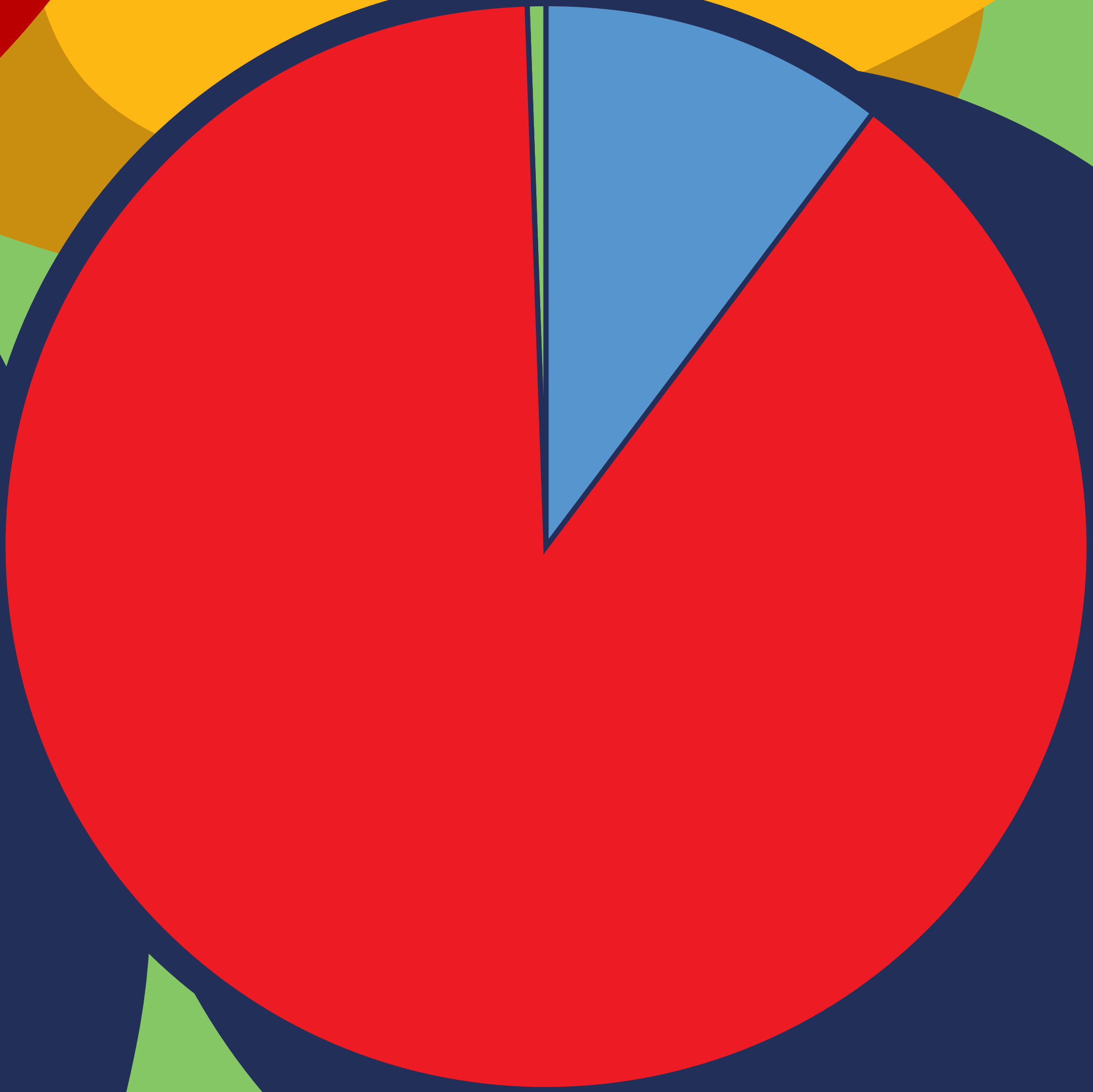
Revenue

Financial Performance

EXPENDITURE

🟦	Raising funds:	10.34%
🟥	Charitable activities:	89.22%
🟩	Governance costs:	0.44%

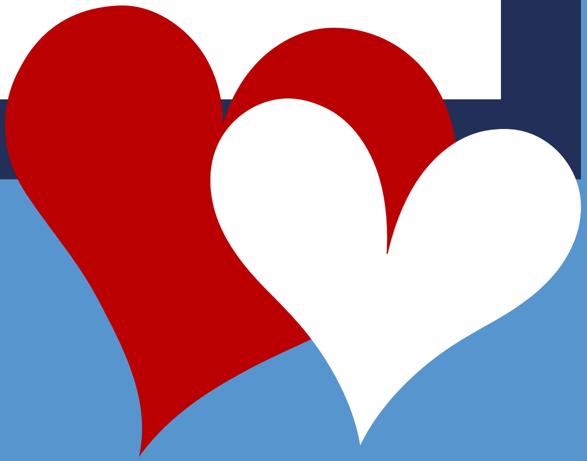
**Expenditure Total:
£531,072**



Donors

Alongside the generosity of our heart families, we would also like to acknowledge those donors who have ensured our services have continued and developed over the last year:

Cavanagh Kelly, NFU Mutual, Hannon Transport, Institute of Civil Engineers, NI Football Association, Dormant Accounts Fund NI, Ulster Garden Villages, Department of Communities Carer's Fund and Community Foundation Mental Health Fund.



Fundraising

The vital services we provide would not be possible without the support of our donors.

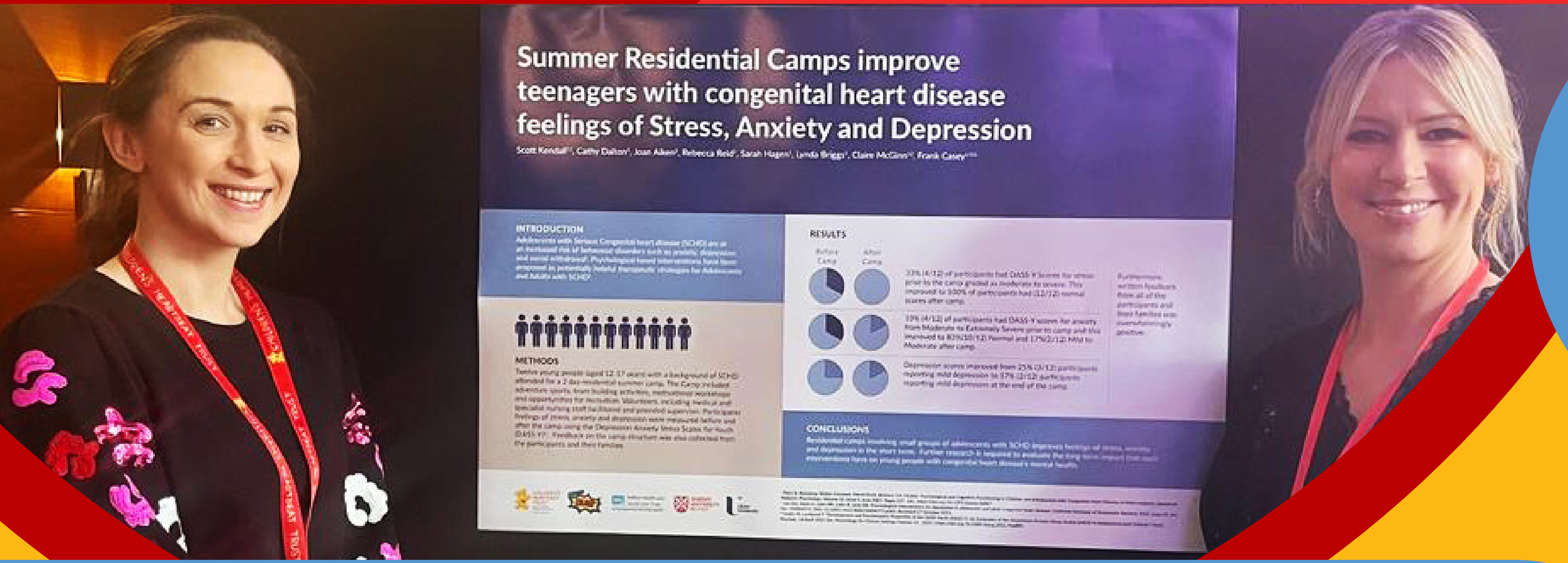
There are too many to mention individually but we are so grateful to **all our community fundraisers, heart families, trusts, foundations, corporate partners, event participants, and individual givers** who go the extra mile to raise, or grant, essential funds to ensure we can continue to deliver our crucial support to heart heroes and their families.

THANK YOU!

Research

Summer Blast 2023

It has been an exciting year for research development. We have begun to investigate our services more scientifically, including Summer Blast.



Summer Residential Camps improve teenagers with congenital heart disease feelings of Stress, Anxiety and Depression

Scott Kendall, Cathy Dalton, Joan Aiken, Rebecca Reid, Sarah Hagen, Lynda Briggs, Claire McGinn, Frank Casey

INTRODUCTION

METHODS

RESULTS

CONCLUSIONS

- A validated psychometric scale called the Depression, Anxiety and Stress Scale, Youth version (DASS-Y) was used to measure any gains attained over the course of the residential.
- There was a 100% improvement in mental health scores taken at the beginning of camp to those taken at the camp's end.
- 33% scored moderate to severe stress at the start of the camp, compared to 0% with moderate to severe stress at the end.
- 33% scored moderate to extremely severe anxiety at the start of the camp, 0% fell in the moderate to extremely severe category at the end.
- Depression scores improved from 25% reporting mild depression at the start of the camp to 17% at the end.
- These findings were presented at the AEPC Congenital Conference in Milan.

View the full report findings:

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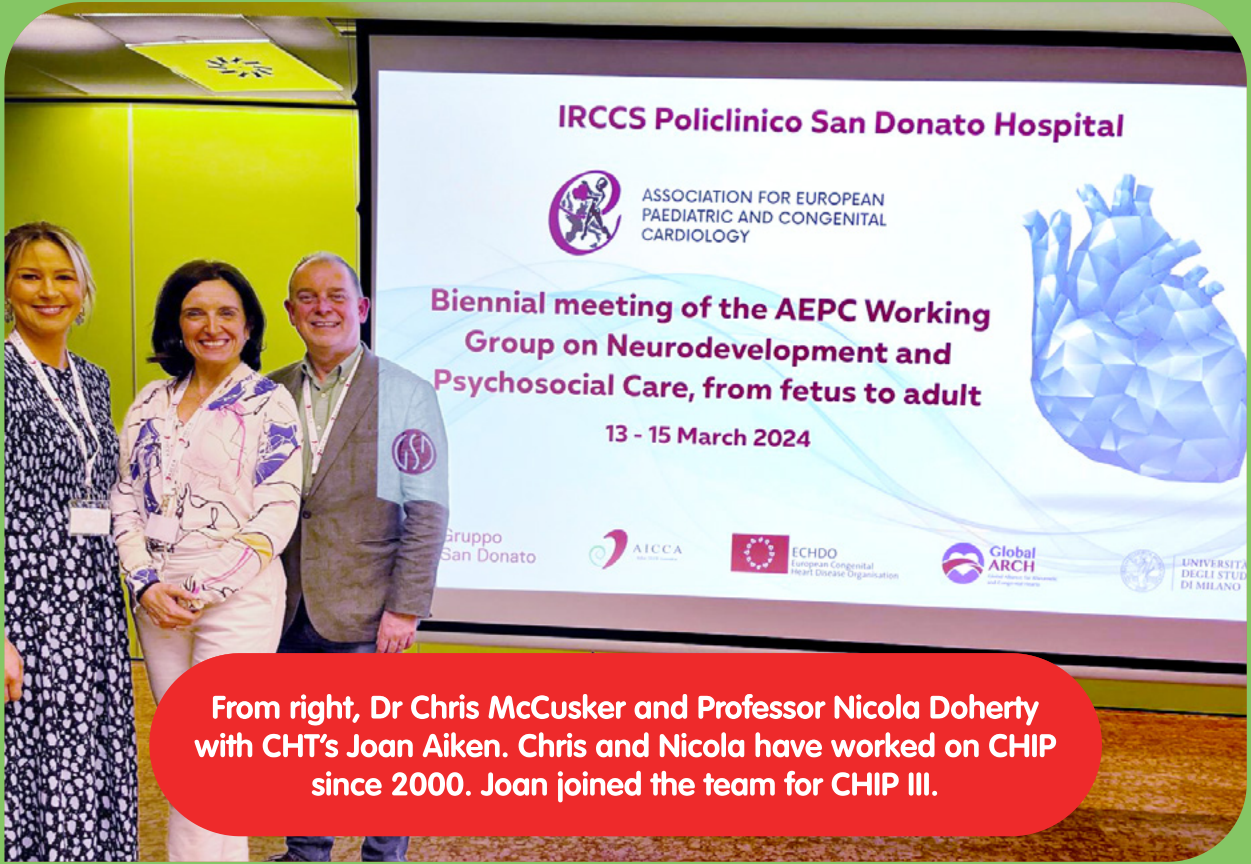
CHIP Research

Back in 2000, we supported a research project to see if a family intervention - Congenital Heart Disease Intervention Programme (CHIP) - could help support better outcomes for children diagnosed with CHD.



From right, Dr Chris McCusker and Professor Nicola Doherty with CHT's Joan Aiken. Chris and Nicola have worked on CHIP since 2000. Joan joined the team for CHIP III.

Those children are now adults. We recently followed up with them to see how they are doing.

This was the third wave of the project, CHIP III. It is hoped the findings from this research will inform future interventions for children with CHD and their families, to help them to adapt and progress as they grow. We are thrilled to be involved in such an important longitudinal research project.

- **53** participants took part in CHIP III.
- **15** parents of young people from our sample took part in 2 focus groups.
- Preliminary findings suggest that the children of the families who received the intervention have improved neuropsychological outcomes.
- Both groups reported similar levels of self-reported psychosocial measures.

Service Development Research

All of our projects have involved families in their design and delivery. This year we have been focused on research into a sibling support service.

- We held 2 focus groups to inform development of new sibling service.
- The 3 main themes identified with 10-13 years siblings were:
  1. Worry about their sibling's health and future
  2. Impact sibling's illness has on daily life
  3. Loneliness
- The three themes were corroborated by the older focus group. However, an additional key theme arose in this group around the lack of knowledge of what was wrong with their sibling and how scary this was.

View the full report findings:

CLICK HERE

SCAN HERE

Sibling Focus Group

Overview:

To gain insights into how siblings of children with CHD are impacted.

Why did we conduct sibling focus groups? CHD is a family affair. We know from speaking with our families that siblings are shaped by the diagnosis, and care that is required, for their brother or sister with CHD. They are often shaped both positively and negatively. We are interested in how we can attenuate the negative aspects of the sibling experience.

The data from the focus groups will be used to inform a new pilot sibling support service for 10-13 year olds which is currently in development.

Focus Group Age Range

Two Age Groups

The two ages groups focused on the target audience of 10-13 year olds, and an older group of 17-21 year olds.

The 17-21 year old focus group was largely to avail of the longer sibling experience and the benefit of hindsight looking back on their 10-13 year old selves.

Three Themes

The three main themes, in order of the strength of vocalisation during the 10-13 year old focus group, were:

1. Worry about sibling's health and future
2. Impact sibling's illness has on daily life
3. Loneliness

"I was at school and I couldn't concentrate at all as I was so scared my brother would die when he was having surgery and I would never see him again. I felt sick all day. Nobody knew."

"It's like really annoying when we are out for a family walk and he takes so long. We always have to go slow and wait because he gets tired."

"Nobody understands what it is like."

"I love my brother so much but it can be really frustrating how everything is always about him being sick."

"Sometimes at night I can't sleep because I worry my brother is going to die."

Additional Insights

From 17-21 year old focus group

The three themes were corroborated by the older focus group. However, an additional key theme arose in this group around the lack of knowledge of what was wrong with their sibling and how scary this was. All of them had taken to researching the condition on the internet and had been overwhelmed by this. In hindsight they wished they had been given accurate age-appropriate information.

"My head went to a way scarier place than it needed to."

"When I look back, I'm kinda mad what was wrong with my sister wasn't explained to me properly."

Conclusion

Siblings are a group that require and deserve tailored support.

- The focus groups were powerful.
- 10-13 year old siblings communicated a strong desire for peer support from other siblings.
- Parents of the 10-13 year old group reported that siblings felt validated and uplifted by the focus groups.
- The themes identified aligned with the academic literature and will be used to inform our service.

All-Island Play Specialist Research

CHT and Children in Hospital Ireland were jointly awarded funding by the Community Foundation's All-Island Fund to support progression towards a fairer, more equitable society on the island of Ireland.

- The funding was used to research the provision of health play specialists on the island and to hold a seminar for those working in both jurisdictions.
- Health Play Specialists help children mitigate the fear, anxiety, trauma and isolation often associated with medical procedures and hospital stays. They achieve this through the medium of play.
- 26 Health Play Specialists work in NI, 21 are based in the Royal Belfast Hospital for Sick Children.
- There are currently 0 policy documents in NI for Health Play specialists or hospital play.
- In the 1990s and early 2000s, hospital play was prominent in policy documents.
- 35 professionals associated with Play and 2 senior staff from the Department of Health attended our seminar to learn more about health play.
- The remainder of the fund is being used to enable play specialists to come together to share best practice and drive change at both a health care setting level and at a policy level across the island of Ireland.

View the full report findings:

CLICK HERE

SCAN HERE

The State of Play

An All Island Approach

Summary discussion and recommendations arising from an all island seminar held in Daisy Lodge, Newcastle, Co. Down on January 25th 2024.

Policy

NORTHERN IRELAND
Currently no policy document in NI for hospital play or health play specialists. In the late 1990s and early 2000s, its importance and the role of play specialists was prominent in policy documents.

REPUBLIC OF IRELAND
Role of play in hospital was significant in the 2004 National Play Policy, 'Ready Steady Play'. A new play policy is expected to be drafted in 2025 - it is unclear at this time if play in hospital is to be included.

Regulation

REGULATORY BODY
There is no regulatory body in ROI or NI. However, it is strongly encouraged across both jurisdictions to register with the Health Play Specialist Education Trust (HPSET).

General

Health Play Specialists help children mitigate the fear, anxiety, trauma and isolation often associated with medical procedures and hospital stays. They achieve this through the medium of play. This can be particularly important for those with serious, chronic, or terminal illnesses, or those with emergency admissions.

PREVALENCE
1/10 adults who attended hospital regularly as a child report mental health issues in adulthood associated with the experience.

TRAUMA INFORMED CARE
TIC is a new medical approach gaining traction globally – play specialists are an important part of this approach.

PLAY THERAPIST VS PLAY SPECIALIST
A Play Therapist helps any child with an identified well-being issue. A Health Play Specialist helps a child receiving a health care intervention and tries to mitigate a well-being issue (typically trauma and/or anxiety) arising from the experience.

Education

DEGREE COURSE
A foundation degree in Health Play Specialism is essential. There is no degree course available on the island of Ireland.

Volunteers

VOLUNTEER NETWORKS
Volunteers play a crucial role in supporting play specialists in ROI. This is managed by Children in Hospital Ireland. There is no equivalent charity in NI and as such no volunteer network in NI.

Research and Collaboration

DRIVING CHANGE
There is opportunity for Health Play Specialists in ROI and NI to work together to drive change. The Taskforce on Children's Play in Healthcare in England, a partnership between NHS England, Starlight, HPSET and other stakeholders, is a collaboration to emulate.

Provision

NORTHERN IRELAND HEALTH PLAY SPECIALISTS
26 HPS in NI - 21 in Royal Belfast Hospital for Sick Children.

REPUBLIC OF IRELAND HEALTH PLAY SPECIALISTS
38 HPS in ROI, in a combination of full and part time positions. 27 of these are in the 4 National Childrens Hospital's in Dublin. There are 11 HPS in 8 regional hospitals with children's wards, an increase of only two across the regional hospitals since the figures reported in 2004 National Play Policy. There remain 9 regional and specialist hospitals with children's wards with no HPS.

■ HPS In Belfast
■ HPS in the rest of NI

■ HPS In Dublin
■ HPS in the rest of ROI

Recommendations

1. Galvanise the wealth of knowledge amongst Health Play Specialists in NI and ROI, and together with stakeholders, drive change.
2. Ensure availability of degree level education on island of Ireland.
3. Increase the policy commitment to play in hospital at government level in both jurisdictions.

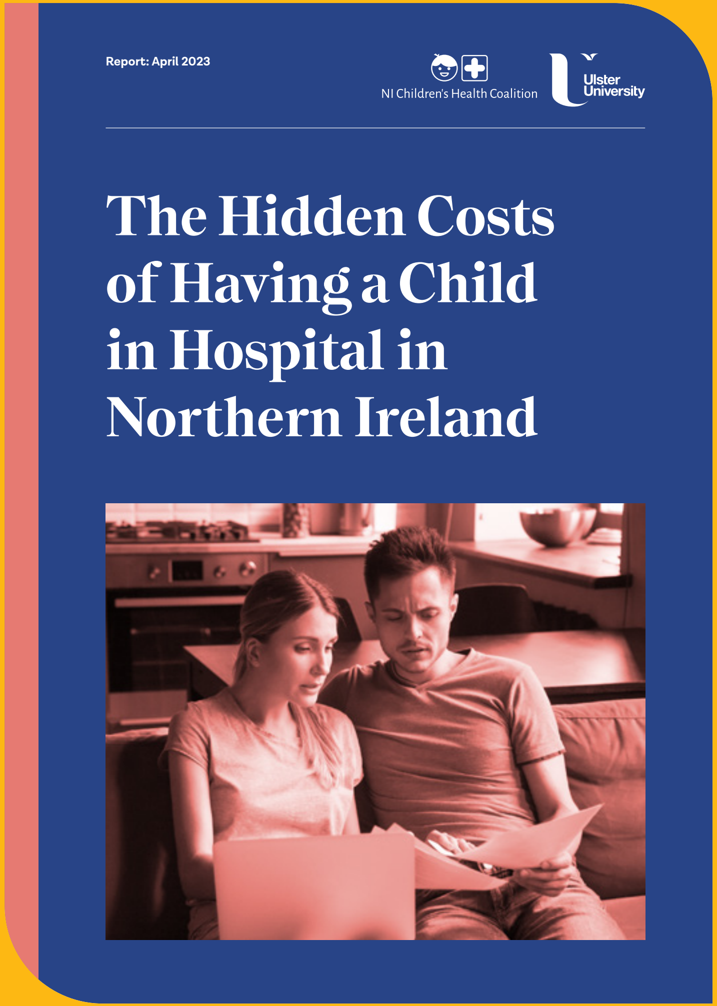
Children's Heartbeat Trust and Children in Hospital Ireland

Policy

Young Patients Fund

Northern Ireland Children's Health Coalition (NICHC) is made up of 15 children's health charities. CHT is a co-chair.

- The aim of the coalition is to improve the quality of health services and holistic support for children and young people in Northern Ireland and their families.
- NICHC commissioned Ulster University to undertake research into the hidden costs of hospital stays and long-term treatment plans.
- The research was launched in June 2023 at Stormont.
- Caregivers reported substantial financial burdens associated with their child's inpatient care.
- The stress endured by families when a child requires extended hospital care is compounded by these financial difficulties, negatively affecting family physical and mental health.
- NICHC has called for a Young Patients Fund to assist with hidden costs. Proposed one off £500 payment, non means tested.
- To date, we have met with all the main NI political parties to discuss the proposed fund and they have all pledged their support.



Report: April 2023

NI Children's Health Coalition

Ulster University

The Hidden Costs of Having a Child in Hospital in Northern Ireland

We are also members of the newly formed Children in Northern Ireland (CiNI) Children's Policy Forum.

View the full report findings:

CLICK HERE

SCAN HERE

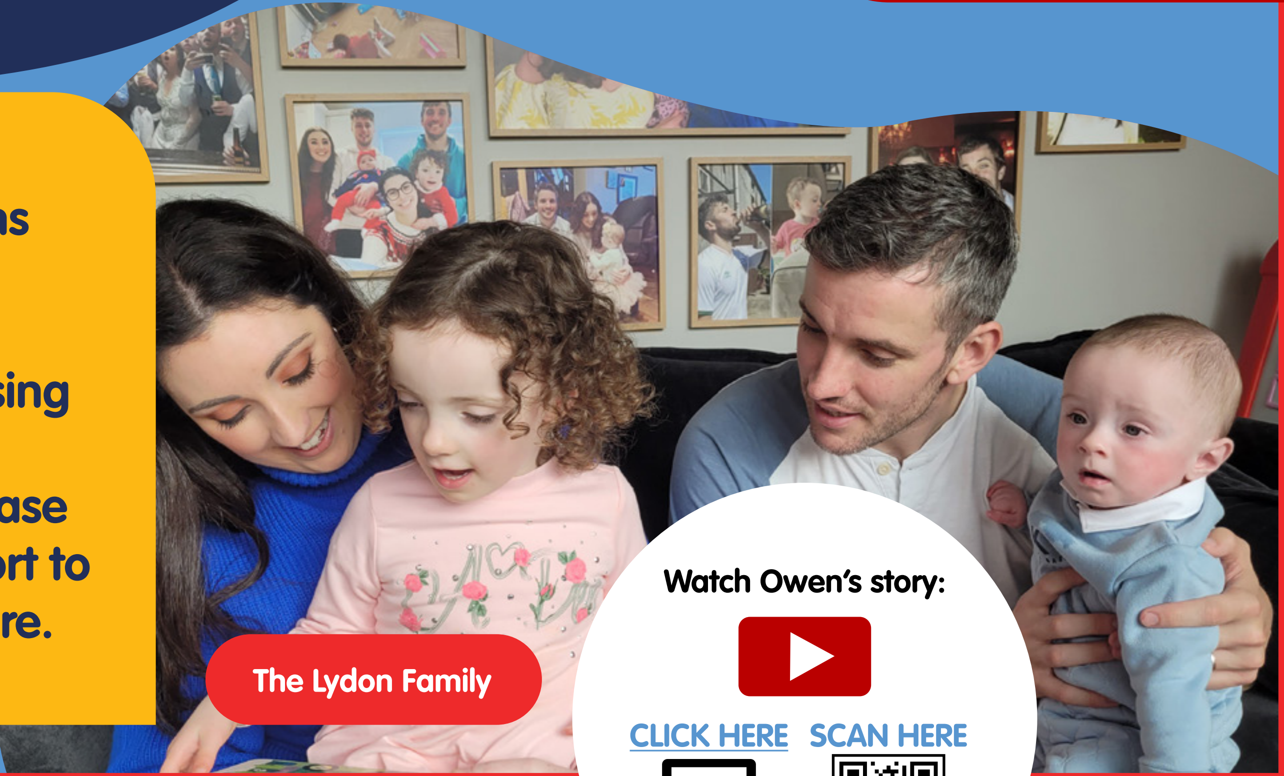
Communications & Awareness

Heart Family Stories

We want to say a massive thank you to everyone who has contributed their personal stories to us, we feel so privileged to be able to share them.

The **Lydon family** is just one of the many families who have shared their story with us. In 2023, Hollie & Darragh (Mum and Dad) celebrated their first Christmas with Owen who was born with a major congenital heart defect, along with his older sister Annie.

Telling our Heart Heroes stories remains at the core of our communications and allows us to keep raising vital awareness of congenital heart disease but also brings comfort to other families out there.



The Lydon Family

Watch Owen's story:

CLICK HERE SCAN HERE

Children's Ambulance 1st Birthday
1st February 2024

In 2023, we launched Northern Ireland's first bespoke Children's Ambulance. The purpose was clear, to provide children and their families with a welcoming and comforting space in which to travel at a time when anxiety is often at an all-time high.

Since then, over **200** trips have been made by the ambulance, providing families and children with a less stressful journey to life-saving surgery.

According to statistics from the Northern Ireland Specialist Transport and Retrieval Service (NISTAR), **95** trips were made in the Children's Ambulance, to or from Dublin for children needing cardiac treatment or surgery in the last 12 months. Overall, the ambulance made **221** trips for children and young adults needing treatment or surgery.

We celebrated the Children's Ambulance first birthday back in February 2024, along with NISTAR, NIAS and heart mum Emma with her daughter Amber who have both used the ambulance.

Read more about the 1st birthday:

CLICK HERE

SCAN HERE

> **"The journey was much easier, more relaxing and more comfortable compared to an ordinary ambulance."**
> **Emma, Heart Parent**

From left, Vicky Hart NISTAR, Paul Johnston NIAS, Niall Parfitt, Board Director Joanne McCallister, Chief Executive, Emma McConnell, Heart Mum and her daughter Amber, Laraine Redmond NISTAR and Cara Barbour NISTAR.

Social Following

Our network of Facebook followers has reached **239.6k** people.

Our Instagram community reached **13.6k** people.

We have **1,982** followers on X (Twitter).

We have **395** followers on LinkedIn

Our YouTube channel was viewed **73,210** times.

Our website had **55,353** page views and **13,506** users.

There were **17,624** sessions on our website.

www.childrensheartbeattrust.org

Plans for the Future

2023 – 2027 Strategy

The four pillars of our future plans are:


Children's Heartbeat Trust
Strategy 2023-2027

Children's Heartbeat Trust's Board of Directors launched our 2023 – 2027 strategic plan this year.

1. Continue to deliver & develop excellent support services for our heart children and their families at all stages of their lives.
2. Ensure the voice of young people and their families are always at the centre of what we do.
3. Inspire more people to give.
4. Inspire our Staff, Board and Volunteers to deliver impactful outcomes for our families.

40 Years

In 2024 we celebrate 40 years of Children's Heartbeat Trust.

We want to say a massive thank you to all our donors, volunteers, healthcare professionals and of course, most importantly, our heart families, who have been with us along the way - we couldn't do it without you all.

THANK YOU!

40 YEARS CARING FOR YOUNG HEARTS

CHILDREN'S HEARTBEAT TRUST
Northern Ireland's Children's Heart Charity

1984

- **1984 – 2009** Voluntary led services developed and grew.
- **2009** Charity appoints first employee.
- **2011** Charity rebrands to Children's Heartbeat Trust
- **2011 – 2013** MRI Scanner Appeal. Along with 3 other charities we raised £2 million pounds to help purchase an MRI Scanner for the Children's Hospital in Belfast.
- **2012** NI4kids Awards – Winner of Family Support Organisation of the Year.
- **2012 - 2014** 'Hands Up for Children's Heart Surgery' Charity campaign to save children's heart surgery in Northern Ireland.
- **2014** Paediatric cardiac surgical services cease in Belfast for babies and children with CHD.
- **2014** All Island CHD Clinical Network is established between Dublin and Belfast.
- **2015** Co3 Leadership Awards – Winner of Leading on Political Impact.
- **2016** MRI Scanner Unit opened at the Children's Hospital.
- **2017** Development of Children's Heart Centre. Children's Heartbeat Trust raises £50,000 for the development of the Children's Heart Centre to ensure the area is child and family focused, providing a world-class service to heart families across Northern Ireland.
- **2018** Sarah Quinlan, our CEO (2014-2022) is awarded an MBE for services to children and young people with CHD.
- **2018** Family First Awards – Winner of Best Organisation Supporting Families.
- **2019** Heart Centre is officially opened by Rory Best MBE
- **2023** Launch of N.I. 's first Children's Ambulance. Following a hugely successful 'Mile A Day' fundraising campaign in 2021 we donated £100,000 to develop a bespoke ambulance in collaboration with the Northern Ireland Ambulance Service (NIAS), and the Northern Ireland Specialist Transport and Retrieval (NISTAR) service.
- **2023** Co3 Leadership Awards – Winner of 'Team up and Save the Day' in recognition of our partnership with NISTAR and NIAS.
- **2024** Children's Heartbeat Trust now has a team of 3 full time staff, 6 part time, an established board of 10 voluntary Directors and 13 regular volunteers running our support groups across N.I.

2024

Year In Numbers

2023/2024

135
ward visits made to
319
heart families

58
antenatal families supported through pregnancy

24
bereaved families supported through our CHT STARS programme

29
parents trained in Infant Massage

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13,506
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100%
mental health improvement for young people after Summer Blast 2023

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216
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40 YEARS CARING FOR YOUNG HEARTS

CHILDREN'S HEARTBEAT TRUST
Northern Ireland's Children's Heart Charity
Charity no: NIC 102410

Registered with FUNDRAISING REGULATOR

The Charity Commission for Northern Ireland

Instagram: childrensheartbeattrust

Facebook: childrens.h.trust

LinkedIn: children-s-heartbeat-trust

X: @Chldns_Hrtbeat

YouTube: @childrensheartbeattrust

Spotify: Children's Heartbeat Trust

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Charity Number: **NIC102410**