



CHILDREN'S
HEARTBEAT
TRUST

Northern Ireland's
Children's Heart Charity
Charity no: NIC 102410

Annual Report

April 2018 – March 2019



A message from Chair & Chief Executive

Children's Heartbeat Trust has a vision of a society that provides high quality and inclusive clinical, practical and emotional support for families at each stage of their journey.

200 babies are born each year in Northern Ireland with a congenital heart defect. We are deeply grateful for the support we receive that allows us to develop existing services, introduce new services and work in partnership with the paediatric cardiology team at the Royal Belfast Hospital for Sick Children as we travel along the road to achieving this vision.

We are particularly proud of our practical and emotional support for heart families throughout the transition to the All Island CHD Network service, and our strong advocacy work in ensuring that heart families are at the centre of all decisions made as this unique network grows.

The small staff team works hard to improve the lives of each heart family, young person and child they meet and we are very grateful for their passion and commitment to the charity and our families. We are also deeply appreciative of our voluntary Board of Directors whose counsel and expertise enable the charity to grow with integrity, transparency and accountability.

We hope that the selection of achievements detailed in this report fills you with the same sense of pride and passion that motivates us at Children's Heartbeat Trust.

Front Cover: Mum Dawn with Lisa



Chair:
Nichola Rooney



CEO:
Sarah Quinlan

Mission and Values

Mission: To support children, young people and their families affected by heart disease in Northern Ireland.

Values: We are a charity that takes its values seriously. We will act in a principled and responsible way in all that we do and we have a strong commitment to the following values.

Professional: From the board, through to our staff team and with our volunteers, we will act in a professional way and always with integrity at our core. We will do nothing to compromise our reputation as a trusted partner in supporting heart families at their point of need.

Heart Family Focused: We are passionate about, and dedicated to, supporting our families and we will do everything we can to provide them with emotional and practical support.

Challenge & Influence: We are committed to delivering the highest possible standards of care and support for our families. Within CHT we will strive to offer high quality support and in the wider environment we will campaign, lobby and collaborate to promote excellent service standards for our families.

Respect & Inclusion: Compassion, dignity and respect are at the core of everything we do.

Partners In Care: We will be at the centre of decision-making that affects heart families. We will engage in co-design, collaborate on initiatives and play a constructive role as partners in care.

We are proud to offer
a wide range of family
support services from
the point of diagnosis
through to adulthood.

Dad Paul with Finlay

Family Support

You provide an invaluable support to families at difficult and worrying times as well as fun events to bring heart families together.

It feels like someone is always holding your hand... I think we would be lost without the charity's much needed support

HEART FAMILY

183

Families attended 39 local family support events

126

Families received financial support when travelling for their child's surgery

109

Parents stayed in our Heartbeat Parent Accommodation

14

Bereaved families attended our first memorial service


The above information is just a small example of the services we offer families.

110

Families holidayed at one of our three respite caravans

Chloe at CHT Family Fun Day





31 Young people have engaged with
our youth services

Youth Services

Ebony, Anna, Amylee and
Megan at SummerBlast 2018

“CHT have made such a difference in our son, Keelan’s, life and his outlook on his heart condition.

LESLEY GAULT HEART FAMILY

Below: Group of young people and nurses at SummerBlast 2018

Youth services has been a key focus for the charity and we are delighted to now offer support to young people living with heart disease from 12 – 21 years old through our BEATZ and TRIBE Programmes.



CHT are a tremendous support to patients and staff. Without their continued support my own role would certainly be more challenging.

CLARK CLINIC STAFF MEMBER

NORTHERN IRELAND
**Children's
Heart Centre**



Clark Clinic & Research

Creating a family friendly environment in the new Children's Heart Centre with sensory panels, equipment and iPads.



Evie playing at a sensory unit in the Children's Heart Centre

The support CHT offer on Clark Clinic is amazing. The friendly faces, having someone to talk to and what you do for the children is brilliant.

HEART FAMILY

6

Pulse Oximeters purchased for Clark Clinic team to give to families

Children's Heart Centre fitted out with sensory panels, equipment and iPads making it a patient and family friendly environment.

27

INR machines provided to paediatric and adult congenital cardiac services through the CoaguChek programme

Recruitment ongoing for delivery of CHIP III with plans for research to start in 2019

Representing Heart Families

We are privileged to be a trusted voice for heart families in Northern Ireland and commit to doing all we can to ensure families can access the best care possible for heart children.

CHT BOARD MEMBER

CHT have lobbied and campaigned on key issues including Brexit implications and hospital waiting lists

Spend of £20,000 on raising awareness of CHD led to the equivalent of
£299,000
media exposure value

Active member of All Island CHD Network Board and Co-Chair of Network Family Engagement Group

Annual Awareness
Campaign with **61** billboards, adshells and bus-sides
across Northern Ireland



JOIN THEIR
BIG FIGHT VS HEART DISEASE

Every year, around 200 children are born in Northern Ireland with congenital heart disease
Text **HEARTS** to 70660 to donate £5 and support Children's Heartbeat Trust.

CHILDREN'S HEARTBEAT TRUST
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www.childrensheartbeattrust.org

Text costs £5 plus network charge. Children's Heartbeat Trust receive 100% of donations. Obtain 960 paper's permission. Customer care 028 9021 2228. Charity Number NIC 123187

CLEARCHANNEL

Harry in our 2018 Billboard Campaign

Representing Heart Families | p10

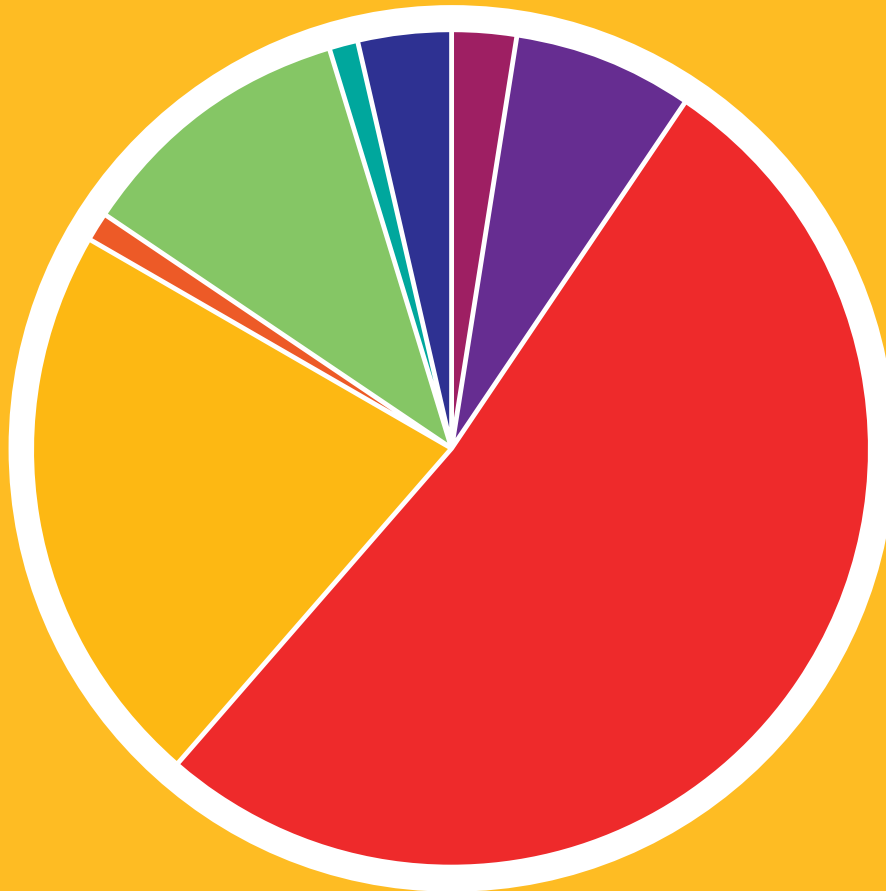
Finance

As we do not receive any government support we are reliant on public donations. Almost 100% of our funding is thanks to the generosity of our wonderful supporters. We really couldn't do it without you.

Your donations totalled an incredible **£373,993** for the financial year 2018-2019.

Costs:

Expenditure and contracted expenditure for this period came to **£426,593**



- Family Support Services: **52%**
- Operational Costs: **22%**
- Information Resources: **1%**
- Awareness & Advocacy: **11%**

- Research: **1%**
- Merchandise & Fundraising: **3.5%**
- Clark Clinic support: **2.5%**
- Administration: **7%**



Thanks to You!

Carol McAdam, CHT
Volunteer at Cultra
Charity Challenge

Over
168
fundraising
events were held
in the community

131
Supporters took
part in CHT
fundraising
events

35
Schools raised
funds for the
charity

10
Organisations
chose us as their
Charity of The Year

133
Volunteers
donated 855
hours to support
the work of the
charity!

Lucy & Chloe with Geraldine
Nolan from National Museums
Northern Ireland



Thanks to You! | p14

Children's Heartbeat Trust

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Note: All quotes are gathered from survey responses, social media and feedback.