



# CHILDREN'S HEARTBEAT TRUST

Northern Ireland's  
Children's Heart Charity  
NIC 102410

Annual  
Report

2016-  
2017



**Mission Statement:  
Supporting children,  
young people and  
their families affected  
by heart disease in  
Northern Ireland.**



## Chairperson's Welcome

As Chairperson, it gives me great pleasure to deliver Children's Heartbeat Trust's Annual Report which sets out the charity's significant achievements during April 2016 – April 2017 and the opportunity to thank the many people who support our work.

The charity has been steadily building capacity to enable us to support and represent heart families as clinical services adapt and transform to meet the expanding needs of patients. This has meant we are now well placed to respond to and support long-awaited changes and new strategic approaches, not least the development of the All Island CHD Network.

As you read through this report you will see inspiring examples of the services offered by Children's Heartbeat Trust, sometimes supporting one family at a time, and other times delivering benefits for our wider heart community. The team at Children's Heartbeat Trust understand that the heart journey is a unique experience – the sum of innumerable individual interactions between patients, families and caregivers. As such, it seeks to aid those interactions in every way possible.

In an ever-changing financial landscape, we are so grateful to our hundreds of supporters across Northern Ireland who have committed their pounds, time and energies to the benefit of our heart families. Without this dedication, Children's Heartbeat Trust would simply not exist.

Maintaining and enhancing the excellence for which Children's Heartbeat Trust is known is our priority now and for the future. We look forward to exciting developments in the pipeline, in particular the new Children's Heart Centre at the Royal Belfast Hospital for Sick Children and the expansion of our Youth Services.

I would like to thank the Children's Heartbeat Trust team for their continued hard work and especially for their genuine passion in wanting to alleviate the difficulties faced by our heart families.

Finally, I would also like to acknowledge my colleagues on the Board of Directors for the commitment, counsel and expertise they bring to the governance responsibilities associated with running a transparent and accountable charity.

**Professor Nichola Rooney**

## Our work in 2016/17

Our work is about helping children and young people with heart disease and their families to live full and empowered lives; informed about their heart condition but not overwhelmed by it.

Our vision is of a society that provides high quality and inclusive clinical, practical and emotional support for heart families at each stage of their journey.

Congenital Heart Disease (CHD) is the most common birth defect in children born in Northern Ireland with on average 200 babies per year born with one or more conditions. One third of these children will face open heart surgery and other interventional procedures throughout their lives.

It is not always obvious to the general public that a baby or a child has a complex heart defect as there can be few visible symptoms, but it is a very serious illness that affects hundreds of families here in Northern Ireland.

We work to support these children, young people and their families. We do this by listening to our heart families and putting in place practical services that will help.

From April 2016 – April 2017 the charity provided support services, information and training to over **500 heart families**. This annual report tells you what this looks like, how we have done this and the difference this has made.

Families have told us they want us to help them with four key areas.

- Supporting Clark Clinic
- Family Support
- Youth Services
- Speaking up for Heart Families



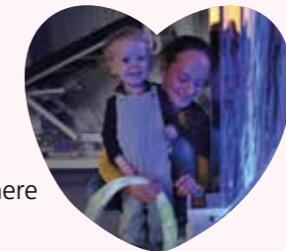
We support Clark Clinic in delivering world-class clinical care for children and their families. We do this in lots of big and small ways from purchasing large pieces of medical equipment costing tens of thousands of pounds to regularly topping up the ward's play specialist's supplies with portable DVD players, games and crafts.

### Sensory Unit

We know that staying in hospital with a sick child isn't only about the tests and examinations but also about helping a child cope with what can be a clinical and scary environment.

Our families told us that one of the most stressful parts of being in hospital or coming for investigations is how upset their child becomes when having to get an ECG. Although it doesn't hurt, for many children the process can be uncomfortable and they become panicked and stressed.

To help we purchased a portable sensory unit to encourage a quiet and calming environment – turning a clinical room into a peaceful, relaxing place. Because it is mobile, it can also be wheeled up onto the ward so the babies, children and parents there can also benefit from its therapeutic value.





**We want heart children to have the best diagnostic and clinical care possible. This means the paediatric cardiology clinical teams having access to the most up to date medical equipment and software available. Due to financial constraints in the health service, this is not always feasible.**

**Portable Echo Machine**

Whenever we can we support the work of Clark Clinic by purchasing much needed medical equipment. This year we purchased a new Portable Echo Machine at a cost of £52,000. An Echo Machine is a vital piece of equipment that performs a non-invasive ultrasound examination of the heart. The pictures produced enable clinicians to gain detailed information about the size and function of the heart chambers, valves and the major blood vessels. High quality images are fundamental to aid in the diagnosis and treatment options for heart children.

Lorraine Davidson, lead physiologist at Clark Clinic explains why this piece of equipment is so beneficial.

*“Being portable means the new scanner greatly improves the service for families across the province, offering improved imaging and increased functionality in a machine that we can bring to outpatients across Northern Ireland and also to the patient’s bedside in Clark Clinic. Our department is so fortunate to have the support of Children’s Heartbeat Trust to purchase much needed equipment in these difficult times.”*



**26**  
CoaguChek machines purchased



**5**  
Sats monitors



**111**  
Parents/couples stayed in our parent accommodation at RBHSC



**An Echo Machine is a vital piece of equipment that performs a non-invasive ultrasound examination of the heart.**

# Supporting families when they need us



## Travelling for Surgery

This year we provided financial support to **123** families travelling outside of Northern Ireland for their child's heart surgery or treatment. Heart parents tell us that having to hand over your child to undergo surgery or catheterisation is incredibly stressful and heart-breaking.

We also know that having to travel for surgery brings additional financial burdens for families who often have to meet additional childcare costs for siblings left at home and take time off work leading to a loss of earnings.

Every family that has to travel for surgery or treatment is eligible for our financial support and we are really proud that through it, and the regular contact from our Family Support Worker, Cathy, we are able to alleviate a little of the stress this situation brings for heart families.

*"The financial support the charity offers when we have to travel to Evelina Children's Hospital in London and the emotional support from Cathy makes a huge impact on our lives. Without it we feel we would not be able to cope as well as we do."*

**Neale Buick, dad to Max (3) who has had two open heart surgeries at Evelina Children's Hospital, London.**

## Support on Clark Clinic

Many of our heart families have to stay on Clark Clinic for periods of time, whether waiting transfer for surgery, recovering post-surgery, or for ongoing monitoring of a child's condition.

To help families when they are on Clark Clinic we provide a range of emotional and practical support including regular contact with our family support team, financial support and parent accommodation.

In this year **111** parents and couples stayed in our Heartbeat 4-bed flat.

**Peter & Diane Gilmour:** *"We spent eight months with our daughter Olivia in Clark Clinic throughout which the clinical team and Children's Heartbeat Trust were a lifeline to us. They have looked after Olivia and us as parents so well during this difficult period in our lives and continue to do so. We could never thank them enough. Children's Heartbeat Trust provided us, amongst many things, with a room at the Royal when Olivia is admitted which means we can stay with her instead of travelling for two hours every day."*

## Counselling



Heart families tell us that having a child or young person with heart disease or facing the prospect of heart surgery can be an overwhelming experience. We know that feelings of anxiety and stress which can result in disruptions to relationships and family life is a normal response to the challenges of living with heart disease and we want to help our families work through these feelings to improve their mental health and well-being.

We run a free, confidential counselling service to give families the opportunity to talk to trained professionals than can offer 24/7 guidance and support and that can be used by individuals, couples and families. In 2016 – 2017 we provided **56** counselling sessions and anonymous feedback highlights that this has been a positive, life-changing experience for those that have used this service.

*“Being able to access the counselling service offered by the charity has really been a lifeline for me. Having someone to talk to and listen to my story at a time in my life that was extremely difficult was invaluable! Thank you CHT for providing such an amazing service.”*

**Heart Parent.**

## Our Caravans

Over the course of 2016 -2017 **69** families enjoyed a break at our two family caravans in Ballycastle and Newcastle. The Courtney family from Carrickfergus told us what this break meant for them.



*“As a family we have thoroughly enjoyed the use of the Children’s Heartbeat Trust caravans. Our son Caleb underwent open heart surgery in August of 2015 at Birmingham Children’s Hospital. Leading up to this surgery and post op recovery has meant that we haven’t left the country for a family holiday in quite some time.*

*The time we have spent at the caravans has been invaluable. As a family we have been able to relax and enjoy quality time together without any fear of being far from medical attention should it be required. These short breaks have been so beneficial in supporting us as a family through an extremely difficult time.”*



## Advocating for Heart Families

As a member of the All Island CHD Network Board and Co-Chair of the Family Engagement Group we have been instrumental in highlighting the need for a successful paediatric cardiac surgical network between RBHSC in Belfast and OLCCH in Dublin, emphasising the impact of travelling to England for surgery for families and the need for a long term financial commitment to the delivery of this network.

In July 2016, the Minister for Health in Northern Ireland and the Health Minister in the Republic of Ireland announced £42M funding for the network. A project that the charity had been actively campaigning for – a new Children’s Heart Centre at RBHSC formed a key element within this commitment, and this new dedicated facility is now due for completion by Summer 2018.

As part of our continued work to improve services for heart families across Northern Ireland, the charity has also pledged £100,000 to ensure that the new Children’s Heart Centre is child and family focused.

With a changing health environment and the development of the All Island CHD Network, it is really important to the charity that we are, and continue to be, a trusted and reliable voice speaking up for heart families in Northern Ireland.



# Youth Services



Our youth services continue to grow. During this year we engaged with 29 teenagers with heart disease.

## Anna

When Anna (13) from Portadown found out about the youth programme offered by Children's Heartbeat Trust she was surprised, as she had no idea there was as much support out there for teenagers with heart conditions.

*"I was diagnosed with Congenital Heart Disease (Tetralogy of Fallot) when I was three days old. Having surgery, and a heart problem in general, isn't easy and I would be lying if I said it hasn't affected my life. Some day-to-day tasks are becoming more and more difficult for me.*

*When I got involved with the charity I was able to meet up with people in similar situations which is so important. They understand my pains and my problems better than anyone else physically can. It has made a huge difference in my life.*



*Over the summer, I was part of teen group for the annual Summer Blast residential. The activities were class and I had a great weekend. The advice I would give to others teenagers with heart problems would be to understand your problem and know your limitations but don't let it hold you back. Most importantly, join a Children's Heartbeat Trust group – it's support has been and continues to be vital for me throughout this journey."*



## World First! CHD Transition App

In 2016 the charity developed and launched the **World's First CHD Transition App** to support teenagers with heart disease as they transition from paediatric to adult care.

Through the app teenagers can directly access information about their clinical services, manage their medication, find out more about their condition and keep in contact with their doctors and medical team.

Download the App for free at 'CHD Transition NI' through iTunes or Android stores.



# Fundraising



## How we can do this

As a local charity in Northern Ireland we currently rely on voluntary donations to fund our services. We are always overwhelmed and appreciative with the generosity of our families and supporters who continue to raise amazing funds.

Our supporters and families make the difference to what services and support we can provide to children and young people with heart disease and their families.

With no Government funding we are indebted to everyone who has supported us in the past year and helped us fund our services to date. Only with your support can we continue to provide and develop our services further so that children and young people living with heart disease can receive the best support and services possible.



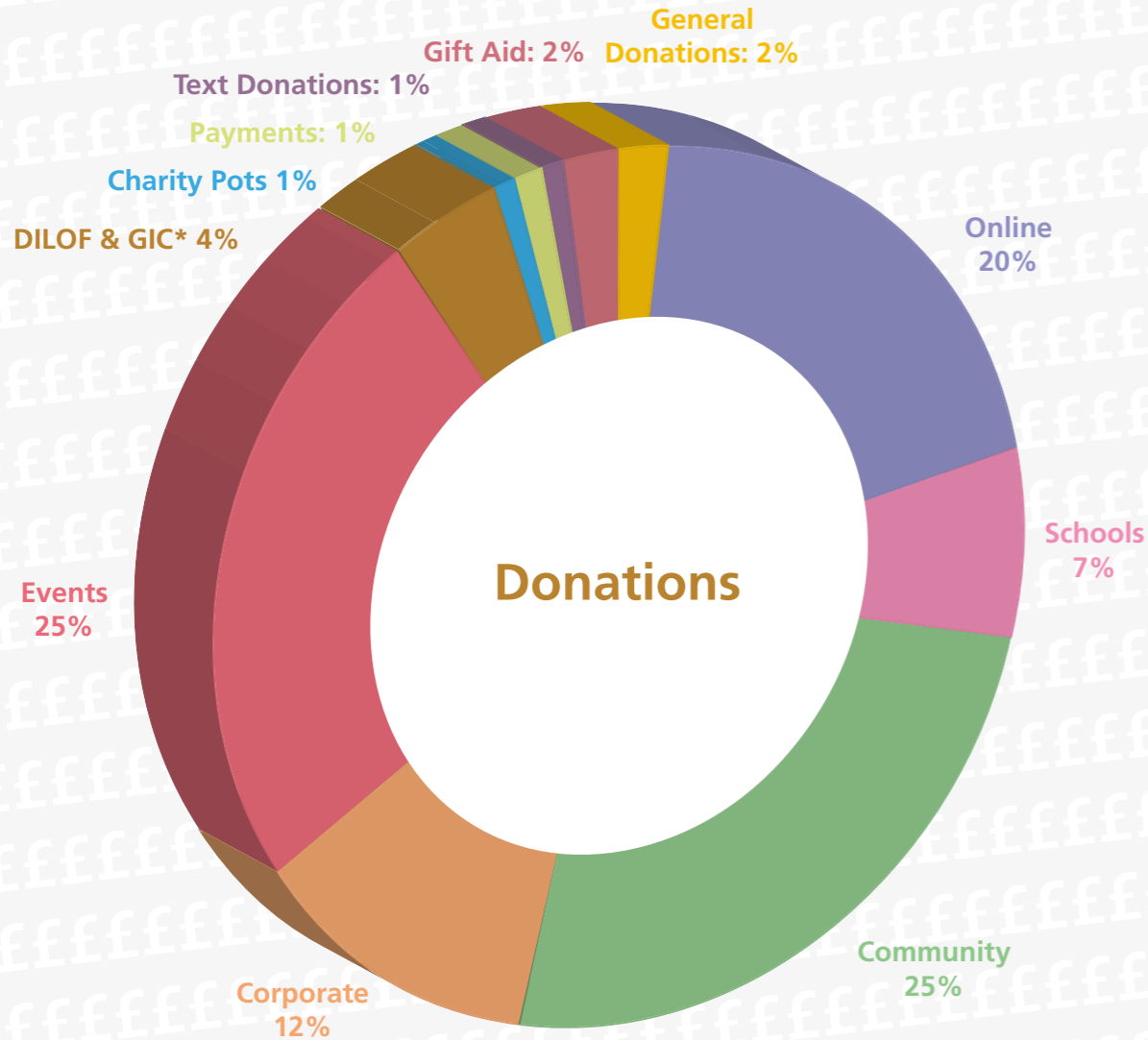
people took part in the 2016 Belfast Marathon raising an incredible £17,000





## Donations

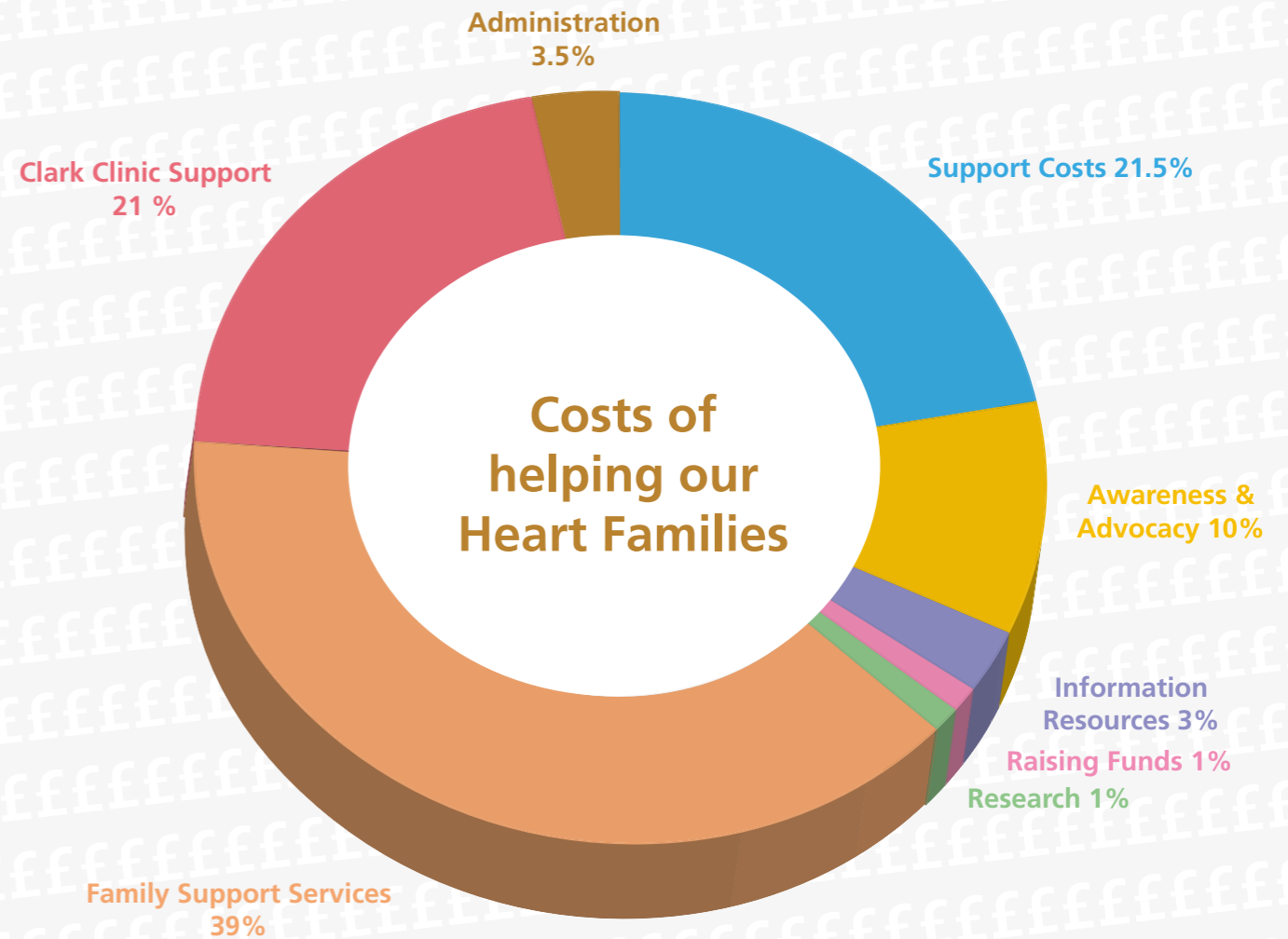
Your Donations totalled an incredible **£444,753** for the financial year 2016-2017.



\* Donations in lieu of flowers and giving in celebration.

## Costs

Expenditure and contracted expenditure for this period came to **£383,434**



# Volunteers

Our work is not only made possible through the incredible generosity of our fundraisers but also through the support and hours given up by our inspirational small army of volunteers. Volunteers share that most precious of resources - their time - to help make life better for those in need.



From April 2016  
– April 2017 **58**  
inspiring volunteers  
donated an  
incredible **320**  
hours to help us.

For us, volunteers are a real lifeline – helping us out in all areas of the work of the charity. Some volunteers sit on our Board of Directors ensuring we follow best practice and are fully accountable, others are busy helping us run the family support groups, while others still are out collecting in shopping centres, cheering on runners at the marathon or helping out in the office.

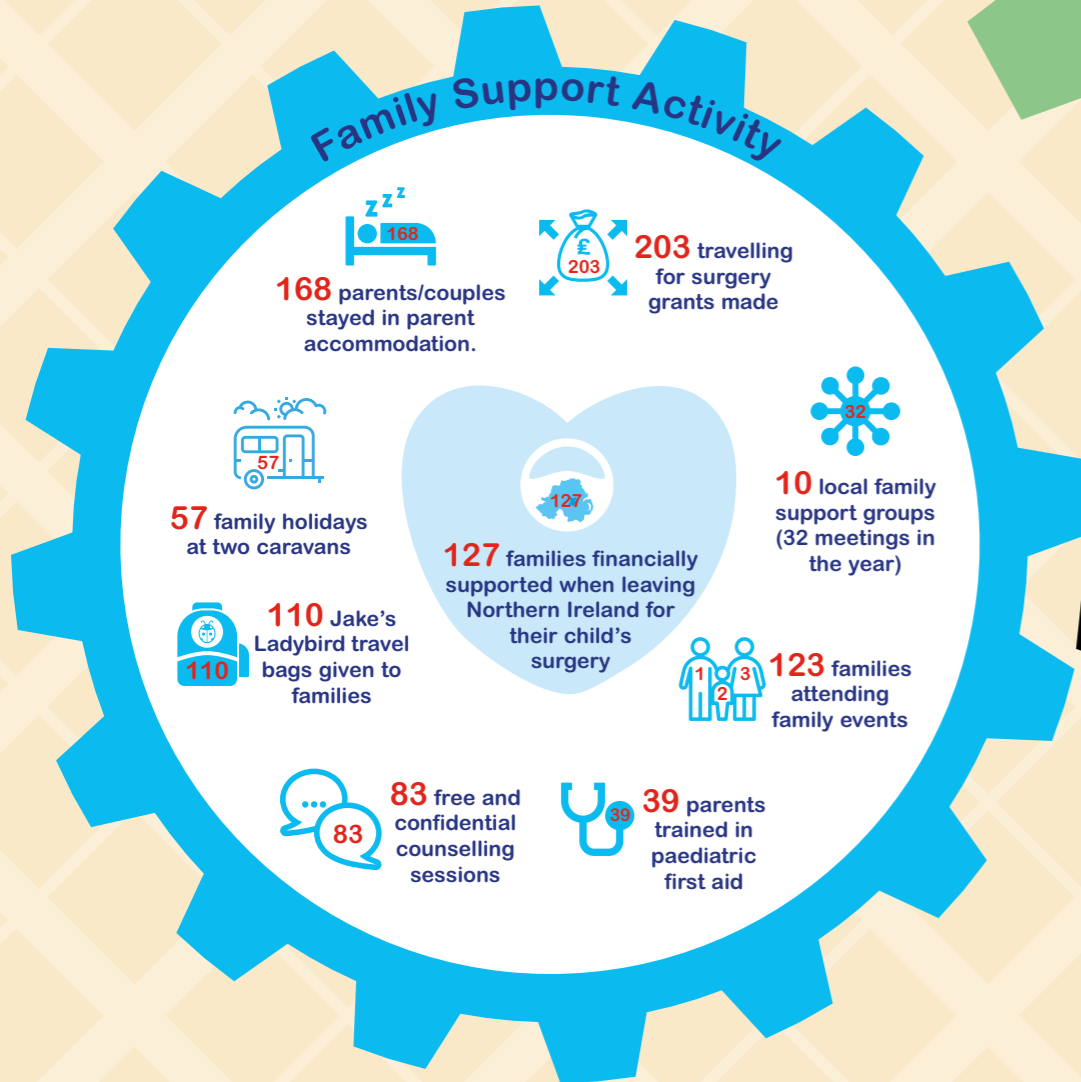
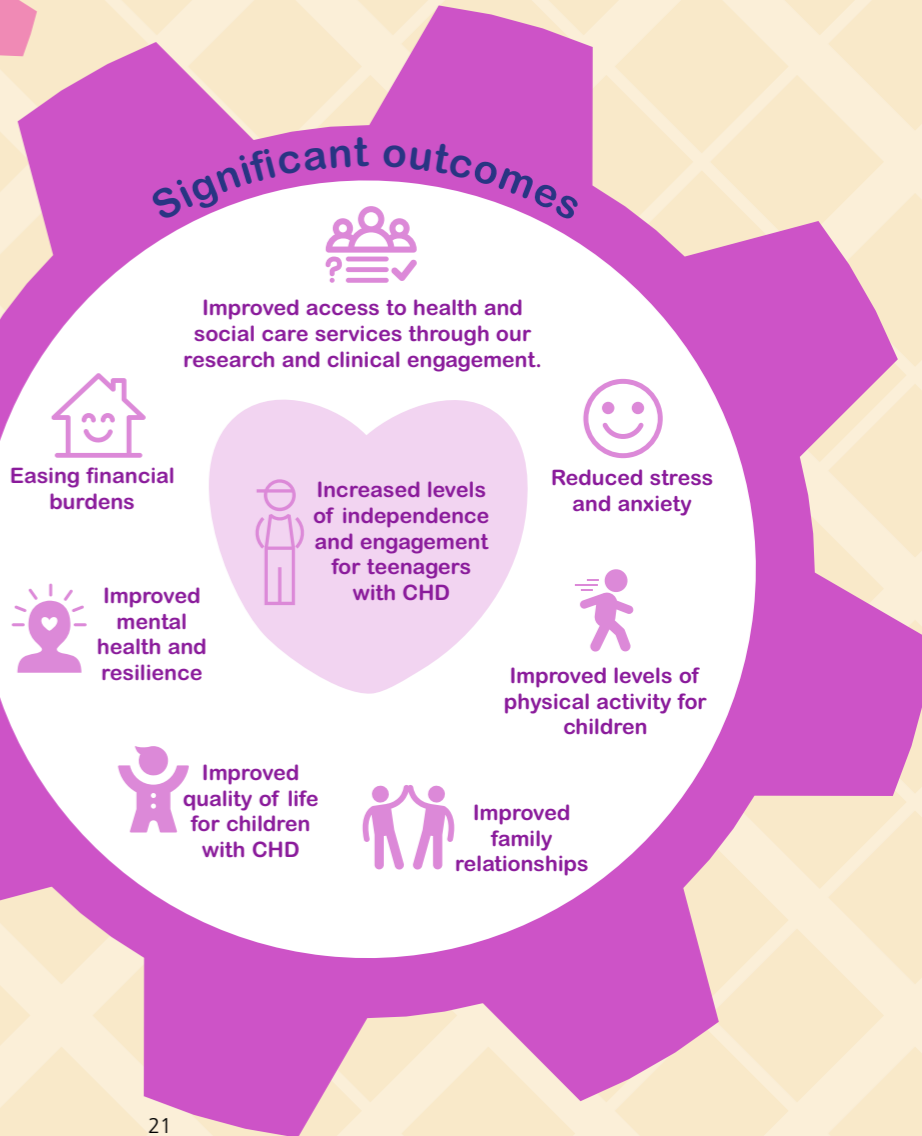
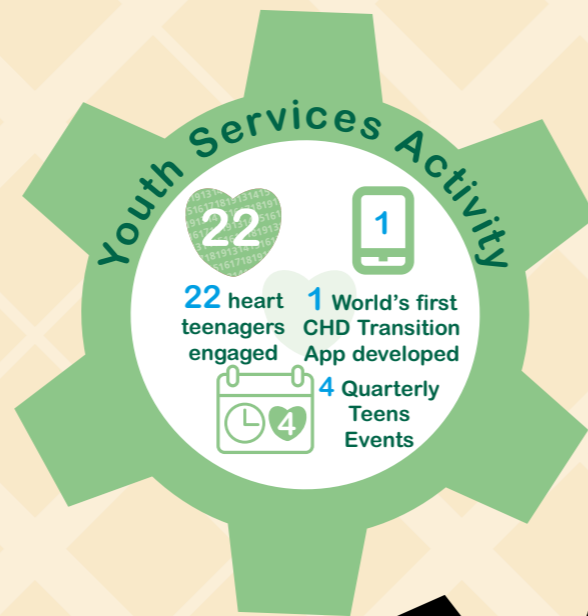
Each and every volunteer has a positive impact on the work we can do in support of our heart families in Northern Ireland.

# Raising Awareness

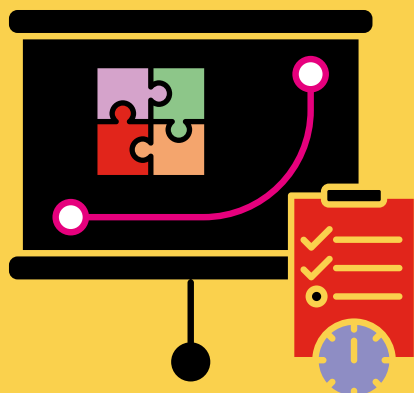


Our Heart Families tell us how important it is that the general public have an understanding of heart disease in children and its impact for these children and their families. So, to raise awareness we run an annual public campaign with advertisements and billboards highlighting what it means for local children and local families in Northern Ireland.

Children's Heartbeat Trust undertook this Social Return on Investment study to better understand the considerable wider social outcomes that are created through our work for children, young people and their families. The study analyses our outcomes for the Financial Year 2015-2016.



# The Year Ahead



**We are always working to address and meet the demands of an increasing number of children, young people and families affected by heart disease. Although we are a small charity we are ambitious to provide as much holistic and practical support for heart families as we can.**

To do this it is vital that we have a clear direction and plan for the next few years. So, with input from our heart families, the paediatric cardiology clinical team and stakeholders we have developed a Strategy that we will implement from 2017 – 2020 focusing on four key areas:

## **Family Support**

– growing our core services and developing bereavement support, schools programmes and support for families travelling for treatment.

## **Youth Services**

– expanding our current teenagers programme and developing innovative ways to engage and communicate with young people to ensure they have the right information to make their own decisions and get on with living their lives.

## **Research**

– developing and funding a programme that supports multidisciplinary research in the area of heart disease in children and young people.

## **Representing Heart Families**

– children's heart services are in a period of transition as the All Island CHD Network develops and our heart families are faced with changes in service in a stretched health care system. We will continue to speak up for families on the issues that matter, advocating and campaigning for their needs and concerns.

## Contact Us



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