



## Message from Chair

This report covers the period of April 2020 – March 2021, when the Covid-19 pandemic cast a long shadow over all our lives, challenging everyone in a multitude of ways.

For Children's Heartbeat Trust, this meant a suspension of all our face-to-face work with our heart families and young people. Lockdown restrictions led to a cessation of many of our services including, the respite caravans, in-hospital parent accommodation, family events and youth residential.

We therefore focused on responding to the most pressing needs that our families faced at this time of great uncertainty and concern. I am so proud of our team who despite the many challenges, adapted and continued to provide services and support to over 400 heart families

I must also acknowledge and thank my fellow volunteer Board members, whose advice and steadfastness provided strong leadership to the charity to help us weather this storm.

The impactful work of our organisation is only possible because of all the fundraisers who give of their time and energy to support us. Not even a global pandemic could stop them from taking on innovative and wonderfully inventive challenges to raise funds. They truly are remarkable.

As we begin to move out of this pandemic, I am confident that we are in a strong position to continue our work with and for heart children, young people and families throughout Northern Ireland.



### Message from **CEO**

In challenging and uncertain times, the role of Children's Heartbeat Trust in providing emotional, practical and financial support to families was shown to be more important than ever. When families were unsure of who to turn to or what advice to follow, we played a vital role in providing tailored information from trusted specialist sources.

Four hundred heart families turned to our support services over this year, and it is thanks to the commitment of our small team that we were able to meet this need, especially for those families facing their child's diagnosis, treatment and/or surgery. We are an incredibly fortunate organisation to have such a compassionate and dedicated team working for our heart families.

I am also grateful for the wisdom, support and advice of all our Trustees, led by the Chair, Professor Nichola Rooney. The efforts of our fundraisers was truly humbling as they confounded all expectations that a pandemic would stop people of generous spirit finding a way to give.

We are looking forward to our full spectrum of services commencing again, enhanced by our learning around COVID-19 which has encouraged us to review and improve their accessibility and delivery for all in the heart community. The enforced pause also enabled us to consider the future of our services and how we continue to work at all levels with clinicians, healthcare professionals, charities, officials and the government, to improve the lives of those affected by CHD. A conversation we will continue to have over the next year as we develop our Strategic Plan 2022 – 2026.

Ultimately, this report highlights that even when the world turns upside down, the strong foundations on which Children's Heartbeat Trust is built make it possible for us to continue to ensure that no heart family will undertake the journey alone, no matter what the circumstances

# Family and Youth Services

We provided financial support to 138 families staying in Clark Clinic and 181 families who had to travel outside of NI for their child's treatment or surgery over the course of this year.



families access counselling sessions.

families were referred through to our ante-natal support service.

bereaved families took part in our virtual Heart Warrior Walk in memory of their child.

Student Bursaries to support education and employment opportunities awarded to young people living with Congenital Heart Disease.

42

children took part in CHT funded in-hospital music therapy sessions.

Provided support to

555 families and

145

children in hardship.

## Family Stories

Our son Aaron was born with a massive hole in his tiny heart, and at seven months old underwent open heart surgery. Honestly it was the support we received from the Children's Heartbeat Trust that made the process somewhat bearable.

They were our "go to" when our baby suffered complications post-surgery and the outcome was very unclear. We relied on them heavily in this time for emotional support and financially they assisted us when our one week stay turned into a three week stay.

#### **THERESA JACKSON**



The Children's Heartbeat **Trust Student Bursary** was a great support in allowing me to complete my studies in Youth Work. My goal is to work with young people with disabilities and support them with opportunities they might otherwise not have been given. It's fantastic to know that CHT is there to support me and other young people like me as we start our careers.



KATIE MULHOLLAND

# Supporting clinical services

### This year 532 families benefitted from the equipment we purchased for Clark Clinic:

- 14 Pulse Oximeters purchased for Clark Clinic team to support families at home.
- Home Monitoring programme provided 18 INR machines to paediatric and adult congenital cardiac services.
- An estimated 500 children were scanned with the VIVID Q scanner funded through the charity.



CHT offers an extremely high level of support to the clinical teams and CHD families.

Family Support Manager

When my daughter was admitted to hospital Cathy (CHT family support manager) was there to support her and make her stay better.

**Heart Family** 

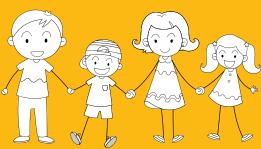
# A trusted voice for heart families

Throughout this year the paediatric cardiology teams at the RBHSC and Crumlin, Dublin worked tirelessly to maintain children's heart services across both sites and ensure babies, children and young people received the care they needed.

Knowing how worrying these times were for families we prioritised the sharing of information from the clinical teams via FAQ's, webinars and regular updates about what restrictions meant for families accessing outpatient and in-patient services.

The charity also founded the **NI Children's Health Coalition**, which we co-chair with Tiny Life. This coalition is made up of 11 children's health charities who all have a focus on improving the lives and experiences of children and families who access hospital services. We know that working together with organisations whose families face similar issues will help us advocate more effectively and improve services for all those impacted by a child's hospitalisation in Northern Ireland.





### **Financial Performance**

#### **DONATIONS:**

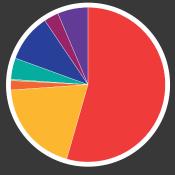
For the financial year 2020-21 your donations totalled an incredible:

**£**412,477

As we receive no government support, our funding is nearly 100% from public donations which is thanks to the generosity of our wonderful supporters.

#### **COSTS:**

Expenditure and contracted expenditure for this period came to £330,873.



- Family Support Services: **54.6%**
- Support Costs: 19.5%
- Information Resources: 1.8%
  - Awareness & Advocacy: **0.3%**
- Research: **4.5**%
- Merchandise & Fundraising: 9.9%
- Clark Clinic support: 3.1%
- Administration: **6.3%**

# Our Supporters

We really have the best supporters in Northern Ireland. As the pandemic and associated restrictions disrupted almost all traditional fundraising events, social media and virtual fundraising became the new norm of fundraising and our wonderful supporters innovated and engaged in new and wonderful ways to support our work. We cannot overstate how grateful we are to each and every supporter who raised funds and awareness at such an uncertain time for our organisation.

Olivia was the face of our first Christmas Appeal.

- 6 charity of the year corporate partnerships
- 190 fundraisers
- Our first ever Christmas Appeal raised an incredible £31,257

### Our Engagement



Twitter: 1.7k Followers - Up 6.8% | @Chldns\_Hrtbeat

Facebook: 15.1K Followers - Up 6.2% | facebook.com/childrens.h.trust

Instagram: 2.3K followers - Up 20.9 % | @childrensheartbeattrust

#### Children's Heartbeat Trust

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