

## CHILDREN'S HEARTBEAT

### REPORT OF THE DIRECTORS FOR THE YEAR ENDED 31 MARCH 2024

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#### Report of the Trustees (incorporating the directors' report) for the year ended 31st March 2024

The trustees are pleased to present their annual directors' report together with the financial statements of the charity for the year ending 31 March 2024 which are also prepared to meet the requirements for a directors' report and accounts for Companies Act purposes.

The financial statements comply with the Charities Act (NI) 2008, the Companies Act 2006, the Memorandum and Articles of Association, and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

#### REFERENCE AND ADMINISTRATIVE DETAILS

The required reference and administrative details are laid out on page 1 - Company Information. The directors of the charitable company (the charity) are its trustees for the purposes of charity law. The Directors serving during the year and since the year end are also included on page 1.

#### OBJECTIVES AND ACTIVITIES

The purposes of the charity are for the public benefit of children, young people, and their families affected by heart disease in Northern Ireland. This is achieved through the provision of emotional and practical support, the advancement and promotion of awareness and the supporting medical resources and research in this area.

In shaping our objectives for the year and planning our activities, the trustees have considered the Charity Commission's guidance on public benefit.

The strategies employed to achieve the charity's aims and objectives are:

- **Financial support for Clark Clinic at the Royal Belfast Hospital for Sick Children:** Clark Clinic is Northern Ireland's only regional unit for children that need specialist treatment for heart conditions. We are proud to have the unique opportunity to work so closely with the Clark Clinic team to help fund top quality medical equipment, sensory equipment and specialist support to ensure that children and young people with heart disease in Northern Ireland receive the best care and treatment possible in an age-appropriate environment.
- **Provision of accommodation at the Royal Belfast Hospital for Sick Children:** Children's Heartbeat Trust maintains accommodation directly above Clark Clinic for parents to stay in when their child is being treated. This allows parents to stay at the hospital in comfortable surroundings, at what is often a traumatic time and especially beneficial for those families travelling long distances to Belfast for their child's treatment.
- **Family Support Groups and Services:** We run ten family support groups throughout the province to provide local support to families when they need it. Our groups are parent led and meet on a regular basis so families have the opportunity to meet other families who are experiencing similar issues and problems in a local, friendly environment.
- **Youth Support:** We operate a dedicated youth support programme to young people diagnosed with CHD. Helping them develop peer support networks and providing social activities, a summer residential and educational sessions, such as transitioning from paediatric to adult care services.

We also deliver a range of support services from bereavement support, family heart books, counselling, baby massage, and music therapy, to peer support and family fun days. These services also include tailored and financial support for families travelling away for their child's surgery.

As a charity, we are also delighted to provide respite caravans for our heart families. Quality family time can be limited if a lot of time is spent in hospital for treatment of a child's heart defect. We see how important it is to have time together as a family for parents, heart children and siblings, and the caravans are a key resource in helping families affected by CHD have a holiday and quality time together.

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#### OBJECTIVES AND ACTIVITIES (CONTINUED)

- **Research into heart disease in children:** We aim to fund and support research into the causes and treatment of heart disease in children. This research will improve health and lifestyle outcomes for children and young people living with heart disease.
- **Campaigning:** The charity campaigns on policy issues that will improve outcomes and lifestyle for children and young people with heart disease. As a member of the All Island CHD Network Board and co-chair of the Family Engagement Group, the charity ensures parents and families are at the centre of all decisions regarding service provision.

#### ACHIEVEMENTS AND PERFORMANCE

##### NI's Children's Ambulance

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 lifesaving 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.

##### Youth Support Research

This year we began developing research into our services to measure their impact on our families and young people. Including our residential for young people – Summer Blast.

We used 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.

Findings included:

- 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.

##### Family Support

- 216 families received financial support when travelling for surgery, or for long-term hospital stays, totalling £110,400.
- 83 families benefitted from a short break at one of our caravans
- 502 people attended our family fun days across NI
- 24 bereaved families supported through our STARS programme
- 29 parents trained in infant massage
- 58 parents supported throughout pregnancy in our antenatal programme
- 319 families received bedside emotional support whilst their child was in hospital
- 119 families utilised our accommodation service in the Royal Belfast Hospital for Sick Children
- 162 families supported by our local Support Groups

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#### ACHIEVEMENTS AND PERFORMANCE (CONTINUED)

##### Youth Support

- 16 young people took part in our Summer Blast residential.
- 11 young people availed of Transition Support from paediatrics to adult services.
- 11 Student Bursaries granted to young people with CHD moving on to further or higher education. £4,950 granted in total.

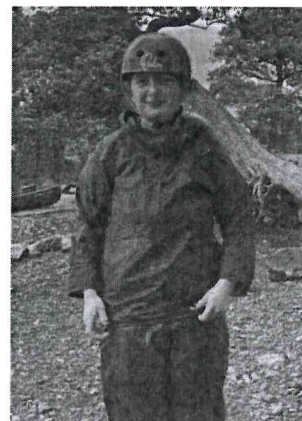
##### Research

###### CHIP

Initial findings being reported from the third wave of this research indicate that the children of the families who received the intervention have improved neuropsychological outcomes.

###### AIN

- Presented the impact of our youth work at the AIN annual conference in January 2023.
- Supporting four QUB/UU PhD projects. Support includes assistance with planning, recruitment and funding applications.



Hope gets ready for adventure at our Summer Blast

##### Service Development Research

All of our projects have involved families in their design and delivery. This year we have focused on research into a siblings support service. We held two focus groups to inform development of new sibling service. The three 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

These insights were corroborated by the older 17-21 focus group along with a new theme of lack of knowledge about what was wrong with their sibling and how scary it is.

##### Advocacy

- Member of CHD All Island Network Board – representing voice of families to the AIN Board.
- Co-Chair of Family Engagement Group – highlighting key issues for furthering family and patient support and engagement.
- Promoting the importance of Organ Donation through social media and a member of the PHA Organ Donation Sub Group; both supporting The Organ and Tissue Donation (Deemed Consent) Bill.
- Co-Chair of Northern Ireland Children's Health Coalition to advocate for families accessing paediatric acute services in Northern Ireland.

##### Cardiac Services

Continued support for paediatric cardiac services in NI through the purchase of medical equipment, sensory equipment and play resources.

- 9 portable SATS monitors allowing families to monitor their child's oxygen saturation at home and for the liaison cardiac team to access accurate information without the family having to travel to a hospital appointment
- 10 CoaguChek machines to empower young people over 16, by training them to safely self-manage warfarin levels, reducing the incidences of complications and hospital visits.
- The redevelopment of the RBHSC courtyard gardens from an HSBC grant.

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#### ACHIEVEMENTS AND PERFORMANCE (CONTINUED)

##### CHT Events

Mile A Day 2023 - £52,558  
Belfast Marathon 2023 - £34,833  
More Than A Gift 2023 - £24,668  
Rock Red 2024 - £22,769

##### Community

Devina Holmes Fundraising in memory of Jordan - £13,011.93  
Sweetheart Boutique/Hollywood Golf Day - £9,964  
Oisin's 1<sup>st</sup> Birthday Fundraiser - £10,300.84  
Berties' Heartbeat - £8,735  
Gibson Primary School - £7,500

##### Corporate Donations

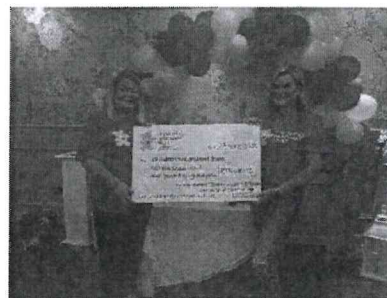
Cavanagh Kelly - £16,372  
NFU Mutual - £6,761  
Institute of Civil Engineers - £7,355  
NI Football Association - £6,000  
Hannon Transport - £7,873

##### Grants

Department of Communities Carer's Fund - £9,950  
Dormont Accounts - £32,237  
Community Foundation Mental Health Fund - £5,592.20  
Ulster Garden Villages - £20,000  
Benefact Group - £5,000

##### Governance

- Four Trustees undertook specialised training sessions from CO3 on governance topics.
- Under the guidance of our Chairperson, the Risk & Governance subgroup began developing new risk reporting.
- A wealth management company was appointed to maximise income from our reserves, in line with CSR.



Devina Holmes presents £13,011.93 raised in memory of her son Jordan on what would have been his 30<sup>th</sup> birthday.



Staff from Cavanagh Kelly embarked on a Heartbeat Hike up the Stairway to Heaven in Co. Fermanagh.

#### FINANCIAL REVIEW

The charity's income for the 12 month period ending 31st March 2024 was £546,152 increasing from the previous financial year (£439,679 in 2023). This year CHT also adopted an investment strategy to maximise income from our reserves, from an initial investment of £400,000, a further value of £27,834 was gained.

In accordance with Section 15 of the Trustee Act N.I. 2001, the Board (the Trustees) of Children's Heartbeat Trust as a limited company and a registered charity prepared and agreed an Investment Policy Statement. The investment objective of the Trustees is that the real value of the Charity assets be maintained and enhanced over the long term by investment in portfolios comprised of equities, fixed income, alternatives and cash, bearing in mind proper attention to investment risks and taking into consideration the needs of the Charity.

Furthermore, as a children's charity, the Trustees do not wish to invest directly in any Publicly Listed Companies (PLC) who are directly involved in the promotion of gambling, the production of tobacco or armaments, in an organisation or area or country with poor human rights records (particularly against women and children) or working conditions, or connected to poor health outcomes or cruelty to children.

Total resources expended of £531,072 decreased when compared to the previous financial year, mainly due to the purchase of the ambulance, with net income for the period amounting to £42,914.

Total net assets amounted to £822,591 as at 31st March 2024 (2023: £779,677).

The majority of funding comes from voluntary donations.

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#### FINANCIAL REVIEW (CONTINUED)

##### Reserves policy and going concern

Children's Heartbeat Trusts' policy is to provide the charity with adequate financial stability and the means for it to meet its charitable objectives for the foreseeable future. The charity aims to maintain reserves at levels equivalent to six months operational expenditure having regards to its manner of operation of likely funding streams. Current levels of reserves are higher than this and until the reserves are utilised, funds will be invested in a number of short to medium term deposits and invested in line with the charity's IPS, to obtain a return in the current economic climate. On making these investments, the ability to withdraw funds if required has been considered.

##### PLANS FOR FUTURE PERIODS

With our new agreed 2023-2027 strategy, Children's Heartbeat Trust has exciting new plans and vision for our support services, research and income generation.

In the next twelve months, we plan to:

##### Family & Youth Services:

- Seek and secure funding to deliver the newly co-designed Youth Programme model.
- Develop an active Youth Council
- Seek and secure funding to deliver a co-designed siblings support programme
- Continued exploration of a 'Home from Home' /family support hub
- Expand on our bereavement support programme
- Continue to develop our podcast series
- Review our pathway to support and points of intervention

##### Research & Policy:

- Disseminate CHIP findings
- Develop a Public Policy Campaign
- Play an active role in supporting the AIN research programme
- Build on our academic partnerships with active support of relevant UU and QUB research projects

##### Paediatric Cardiac Services support:

- Continue to provide support on the ward to families
- Seek longer term funding for additional therapies on the ward e.g. music
- Purchase required equipment to support our heart children

##### Advocacy and Awareness:

- Review the Communications strategy for the organisation
- Develop new projects for the All Island Network Family Engagement Group
- Engage with the new Health Minister on our work
- Continue our lobbying with the NI Children's Health Coalition to launch the 'Hidden Costs of Having a Child in Hospital' research, with a call for financial support for families.
- Campaign for a pulse oximetry test to be standard for all new-borns.
- Continue to develop a catalogue of digital resources for heart families
- New website developed and integrated with CRM

##### Income Generation:

- Implement the new income generation strategy
- Provide robust training / mentor opportunities to current staff
- Generate new and diverse income streams

##### Continued development of robust governance processes:

- Develop and implement a new risk audit
- Hold Board reviews
- Future proof by ensuring Board skill needs are filled
- Ensure compliance with Charity Commission NI requirements
- Maintain registration with Fundraising Regulator following the Regulator's Code of Practice
- Provide training for volunteers and Board Members

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#### STRUCTURE, GOVERNANCE AND MANAGEMENT

##### Governing Document

Children's Heartbeat is a company limited by guarantee governed by its Memorandum and Articles of Association dated 12 October 2013. Children's Heartbeat is a registered charity with the Charity Commission for Northern Ireland. Children's Heartbeat is a membership organisation with currently 10 members, each of whom agrees to contribute £1 in the event of the charity winding up.

##### Appointment of trustees

The Chairman and the Trustees recruit and select new Trustees as needed. New Trustees are recruited on the relevance of their professional skills, and their potential to be able to make a helpful contributions to the governance of the charity. As part of the recruitment process they are made aware of a Trustees' legal obligations under charity and company law, the content of the Memorandum and Articles of Association, the committee and decision making processes, the business plan and recent financial performance of the charity.

Once the potential new Trustee has agreed to be considered for appointment to the role, the Trustees meet to review and to vote on the candidates' suitability for appointment. If there is unanimous agreement, their names are then proposed for appointment, to the voting Members of the Company.

##### STATEMENT OF DIRECTORS' RESPONSIBILITIES

The directors are responsible for preparing the Report of the Directors and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Acceptable Accounting Practice).

Company law requires the directors to prepare financial statements for each financial year. Under company law the directors must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, include the income and expenditure, of the charitable company for that period. In preparing these financial statements, the directors are required to:

- select suitable accounting policies and then apply them consistently;
- make judgements and accounting estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.


The directors are responsible for keeping adequate accounting records that are sufficient to show and explain the company's transactions and disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

##### STATEMENT AS TO DISCLOSURE OF INFORMATION TO AUDITORS

So far as the directors are aware, there is no relevant audit information of which the company's auditors are unaware, and each director has taken all the steps that they ought to have taken as a director in order to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

This report has been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small companies.

##### ON BEHALF OF THE BOARD:

  
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Nichola Rooney (Nov 13, 2024 15:44 GMT).....  
Prof N Rooney - Chairperson

Date: 13/11/2024.....