

CHILDREN'S HEARTBEAT

REPORT OF THE DIRECTORS FOR THE YEAR ENDED 31 MARCH 2023

Report of the Trustees (incorporating the directors' report) for the year ended 31st March 2023

The trustees are pleased to present their annual directors' report together with the financial statements of the charity for the year ending 31 March 2023 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, pioneering research initiatives, sensory equipment and play 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 eleven 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.

We also deliver a range of support services from bereavement support, family heart books, counselling, baby massage, and paediatric first aid training 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.

CHILDREN'S HEARTBEAT

REPORT OF THE DIRECTORS FOR THE YEAR ENDED 31 MARCH 2023

OBJECTIVES AND ACTIVITIES (CONTINUED)

- **Youth Services:** The charity runs two programmes for young people; Beatz for 12 – 16 year olds and Tribe for 17 – 21 year olds. These programmes consist of regular events and workshops and an annual residential weekend giving heart teenagers and young adults the opportunity to build friendships and share experiences.
- **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.

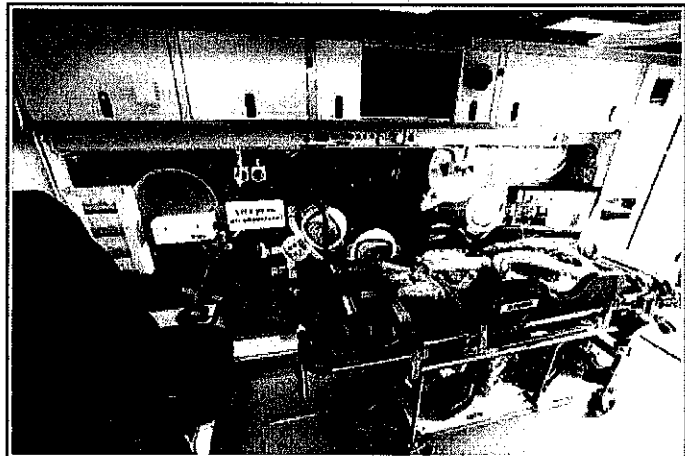
ACHIEVEMENTS AND PERFORMANCE

NI's First Children's Ambulance

In January 2023 we launched NI's first dedicated children's ambulance, in partnership with NISTAR & NIAS. The ambulance was designed bespoke for children making longer journeys, to ensure them greater comfort, less stress, a choice in how to travel and to reduce anxiety. We achieved this by removing the clinical look of the internal features and giving it a relaxing space theme; installing sensory equipment; wheelchair tracks; taking the monitors away from eye lines; and integrating a TV, tablet holder and Playstation with games and DVDs for the journey.

Children's Heartbeat Trust donated £100,000 towards the build of the ambulance and also covered the insurance cost and associated PR.

Priority service will be given to those children and young people who need to travel for cardiac surgery or treatment, when not in use for this it will be available for any child needing specialist transfer.



ABOVE: Interior of NI's first Children's Ambulance.

LEFT: Joanne McCallister, CEO; Roberta & Reuben, Heart Family; and Prof. Nichola Rooney, CHT Chairperson, at the launch of the children's ambulance.

CHILDREN'S HEARTBEAT

REPORT OF THE DIRECTORS FOR THE YEAR ENDED 31 MARCH 2023

ACHIEVEMENTS AND PERFORMANCE (CONTINUED)

Family Support

- 145 families received a financial grant to support them when their child travelled outside NI for treatment, surgery had an extended stay in Clark Clinic, or they suffered a crisis situation. £74,649 was granted in total.
- 190 families received emotional support on the hospital ward.
- 100 families attended support group events across NI.
- 180 families attending peer support /social events across NI.
- 27 families received bereavement support.
- 88 families availed of a short break in Newcastle or Castlerock.
- 123 counselling sessions were attended by 32 families or young people.
- 55 Jake's Ladybird Bags (emergency hospital bag full of essentials) were provided in the last year.
- 110 parents stayed in our parental accommodation at the hospital.



Heart warrior, Sadie, and her sisters enjoy a caravan short break.

Youth Support

- 10 young people supported through peer support events.
- 16 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. £5,000 granted in total.

Research

CHIP

- Data collection completed, scored and sent to Dr Chris McCusker, University College Cork, for analysis.

AIN

- Presented future research priorities at the AIN Research Symposium at Queen's University Belfast.
- Supporting four QUB/UU PhD projects. Support includes assistance with planning, recruitment and funding applications.

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.

- 5 high back chairs purchased for Clark Clinic to make families more comfortable.
- £11,530 of equipment for the clinical team to help reduce wait times for our young people:
 - 5 ambulatory cardiac monitors.
 - 15 Coaguchek machines, purchased for the Home Monitoring Programme.
 - 20 Sats monitors purchased for heart families.
- Pledge to financially support the redevelopment of the RBHSC courtyard gardens from an HSBC grant.

CHILDREN'S HEARTBEAT

REPORT OF THE DIRECTORS FOR THE YEAR ENDED 31 MARCH 2023

ACHIEVEMENTS AND PERFORMANCE (CONTINUED)

Income Generation

Key CHT Events

Mile A Day in May raised £31,580.10.

Rock Red raised £22,873.14.

More Than A Gift Christmas Appeal generated over £22,000, with an additional £25,000 donation from Almac.

Key Community Events

Benone Caravan Park raised £12,160.31.

Limavady's Cycling Farmers raised £9,893.31.

Corporate

Savills held a Bingo Loco night raising £20,014.97.

Trust applications

BGF Foundation granted us £5,000 to support the Christmas Appeal Hardship Fund.

Liberty IT awarded us £4,400 to support our Take Ten App.

Danske Bank granted us £4,467.14 to purchase two Ambulatory Cardiac Monitors.



Savills present CHT with £20,014 raised from their Loco Bingo Night.

Governance

- CRM system set up complete.
- Strategic review completed, 2023-2027 strategy developed.

FINANCIAL REVIEW

The charity's income for the 12 month period ending 31st March 2023 was £439,679 decreasing from the previous financial year (£586,554 in 2022, but increasing from £412,477 in 2021).

Total resources expended of £609,707 increased when compared to the previous financial year, mainly due to the purchase of the ambulance, with net expenditure for the period amounting to £170,028.

Total net assets amounted to £779,677 as at 31st March 2023 (2022: £949,705).

The majority of funding comes from voluntary donations.

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 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:

CHILDREN'S HEARTBEAT

REPORT OF THE DIRECTORS FOR THE YEAR ENDED 31 MARCH 2023

PLANS FOR FUTURE PERIODS (CONTINUED)

Family & Youth Services:

- Build the capacity of our Family & Youth Team by recruiting a full time Youth & Family Engagement Officer
- Deliver a Mental Health & Wellbeing programme to our young people
- Co-design a new youth programme to increase our engagement with teenagers
- Develop a Youth Counsel
- Develop an evaluation framework for each service to build data and knowledge in order to make evidence based decisions regarding programme development and funders.
- Research and planning for a siblings support programme
- Continued exploration of a 'Home from Home' /family support hub
- Develop new bereavement support services
- Develop a Heart Podcast series

Research & Policy:

- Recruit a Research and Policy Officer
- Disseminate CHIP findings
- Develop CHT research priorities
- 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
- Develop a family friendly space on Clark Clinic
- Completion of the redevelopment of the Children's Hospital Gardens
- Purchase equipment to support our heart children

Advocacy and Awareness:

- Seek funding for and recruit a Communications Manager
- Develop a Communications strategy for the organisation
- Develop new projects for the All Island Network Family Engagement Group
- Work 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.
- Develop a catalogue of digital resources for heart families
- Seek and secure funding to begin website redevelopment and integration with CRM

Income Generation:

- Review income generation and develop an income generation strategy
- Provide robust training / mentor opportunities to current staff
- Generate new and diverse income streams
- Develop digital fundraising opportunities

Continued development of robust governance processes:

- Develop an investment policy
- Hold Board reviews
- 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

CHILDREN'S HEARTBEAT

REPORT OF THE DIRECTORS FOR THE YEAR ENDED 31 MARCH 2023

STRUCTURE, GOVERNANCE AND MANAGEMENT (CONTINUED)

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 contribution 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:


.....
Prof N Rooney - Chairperson

Date: 28/11/23
.....