

braveheartsnl

Trustees Annual Report for year ending 31 March 2024



Charity Registration Nr - NI 101055



Executive Summary



2023-24 was a year of incredible highs and devastating lows.

Firstly, I would like to mention the passing of our dear Bravehearts Ben, Lorcan and Roudy. All of whom were in their 20's. We really struggled with the loss after knowing these wonderful boys throughout the past years. Their loss will be felt for a long time, and we will use this sorrow to spur us on to reach and support more families in the same situation.

We had yet another remarkable year of connection and friendship. BraveheartsNI continues to be 100% volunteer led with a core of volunteers and public supporters who drive us forward. This has been a bumper year of new businesses and community groups holding fund raisers for us. We continue to be humbled that we are chosen when times are tough for many and yet charity remains important to them.

This past year we had a great many initiatives once again. We continued to help with the cost-of-living crisis, we did what we do best and supported our Bravehearts with food vouchers, energy support top ups and other everyday necessities. We continued to promote mental health engagement with multiple counselling sessions and weighted blankets. We provided numerous exercise equipment and personal training sessions to encourage healthier living and defibs into the communities. The Bravehearts crocheting/crafting group has trebled in size with bundles of beautiful blankets delivered to various care homes and Children Clark Clinic, RVH, Belfast. Hundreds of tiny hats and Octopi for premature babies are constantly crocheted and gifted to Special care units around the country. It has now become a 'crafting' group, including many who wouldn't have the dexterity to crochet, but can-do other crafts. The primary function of the group is all about connection and it is going from strength to strength.

Our volunteers continue to go out and about talking to companies, organisations and community groups telling them about the great work we do. We continued to run education courses to help our Bravehearts with employability skills, building confidence to take a new direction in their lives and inset themselves into an environment of employment which historically has not been a route many were able to consider.

We had another great year of supporting our Clinicians and cardiac wards in RVH. We again sponsored our clinicians to be able to attend training courses in GB.



We also provided the growing team with more MacBooks and online learning technology to advance their knowledge and enable them to teach all things CHD to other medics around the country. We sponsored the first ACHD Obstetric Cardiology Education Day where over 50 clinicians attended from all over the province for training. This was a huge success, and we will be partnering with the ACHD team to do this again. We co-sponsored a Transition Day for Bravehearts and their families who are moving from the children's team to the adult services.

We continued to provide Pulse Oximeters, games, and toiletries to the wards. We also donated many toys and blankets to the Children's Cardiac ward and spent tens of thousands on family & hospital support. There is so much that we do that is so private to the Braveheart that we can't share it with our followers, but supporting our Bravehearts and their families will always take priority over public perception.

We continue to advocate for better services for our Bravehearts, this year the main issue was Patient Travel where we worked with Health Department to make this an easier process.

We had an even larger group attending our annual Christmas Panto and get together. It was such fun and was incredibly heartening to see connections that were made last year have now turned into wonderful friendships.

As always, in conclusion, we must make special mention of all our fundraisers. As we were extremely busy supporting our families, we rely on others keeping our metaphorical doors open. To them we are indebted and humble to receive your kindness. Lastly, I would like to mention our volunteers. Without you we couldn't survive. The pride you have in our charity is the cornerstone of everything we accomplish. Thank you.

We go forward with pride.

#weareyou.

CLARE CAULFIELD

Chairperson





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Honouring the Legacy of our Community Departed

Congenital Heart Disease (CHD) affects nearly 1 in 100 babies born in the UK, with 1 in 4 requiring surgical interventions and lifelong care. Over the past three decades, there has been a significant improvement in the outlook for individuals with CHD, with the survival rate increasing from 20% to 90%.

The severity of these cardiac defects varies, presenting unique challenges for each individual. While some can lead normal lives, others encounter daily hurdles due to their life-limiting condition. Despite advancements in medical interventions and increased awareness, ongoing support and understanding are crucial for individuals and families navigating the intricate journey of living with CHD.

Sadly some of our Bravehearts have their precious lives cut short, and this year is no exception, with three young lives succumbing to their complex CHD.

Let us hold dear the memories of those lost to CHD, honouring their resilience and spirit.



Roudy Azar

18th April 2001 - 19th April 2023

Ben Fullerton

April 1995 - 24th May 2023



Lorcán Mullan

May 2000 - 22nd July 2023

"Gone from our sight, but never from our hearts."



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Overview

BraveheartsNI, a local charity in Northern Ireland, which is 100% volunteer led and provides crucial support to teenagers and adults living with Congenital Heart Disease (CHD). As BraveheartsNI celebrates its tenth year, it reflects on a year filled with both triumphs and challenges.

Throughout the year, BraveheartsNI welcomed new Bravehearts into our growing community, alongside their families and friends, expanding its reach beyond expectations. Despite facing some heart-breaking losses, we remained steadfast in our commitment to supporting our Bravehearts and their families, striving to find solace in the positives amidst sorrow.

The support offered to Bravehearts and their families was tailored to individual needs, ranging from financial assistance during hospital stays to providing exercise equipment, PT sessions, weighted blankets, hoodie blankets, and financial aid for necessities like food and energy bills.

We continue to support the ACHD Team, Cardiac Wards on Level 5 and Clark Clinic in the RVH

A standout event of the year was the collective trip to see the pantomime "Snow White & the Seven Dwarfs" in January 2024, offering a memorable and uplifting experience for all involved.

Additionally, BraveheartsNI remained dedicated to helping our Bravehearts successfully navigating their Personal Independent Payment applications, ensuring they receive the support they deserve.

Aim

BraveheartsNI's aim is to support teenagers and adults living in Northern Ireland with Congenital Heart Disease, by providing pastoral and welfare support to both them and their families.

Objectives & activities

BraveheartsNI continues to foster a peer-to-peer support network for CHD patients in Northern Ireland, now spearheaded by the Bravehearts themselves. All activities undertaken by BraveheartsNI remain 100% volunteer-based, with funds raised or donated directly benefiting individuals within NI.

The Bravehearts are finding strength and camaraderie in collaborating with one another, offering support and encouragement to themselves and fellow patients and families. This concerted effort is making significant strides in alleviating isolation within this small demographic, empowering Bravehearts with a sense of purpose and agency.

Maintaining our status as a 100% volunteer-led charity remains paramount. Our strong ethos has garnered substantial support and donations, reinforcing the importance of our patient-led approach.



Ethos

At BraveheartsNI, we've cultivated a people-centric culture rooted in our core values of compassion, benevolence, and a willingness to assist others. This ethos fosters synergies that unite our team, yielding effective outcomes. Placing people at the forefront, we empower them with responsibilities across all functions, valuing our volunteers' contributions and integrating them into our team while granting them autonomy to spearhead initiatives and manage collective activities. We prioritize training and education to ensure our teams understand and endorse the importance of supporting teenagers and young adults with CHD. Our culture is defined by our commitment to accessibility, inclusivity, and open-mindedness in providing support mechanisms. We foster open communication, consult with our entire team, and welcome feedback at all levels to continuously improve our services.

Strategy

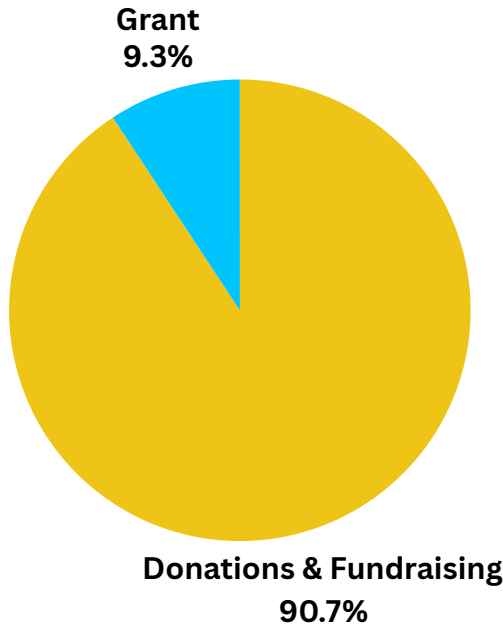
Our strategy has been fluid from the start due to the nature of CHD. No two Bravehearts or their support networks are exactly the same in their needs and everyone deserves a chance to get help and support tailored to their needs. As time progresses we will identify reoccurring issues and areas of need and set a robust response in place which will encompass the core of the issue.

Policy

Since conception, our steadfast commitment has been to maintain a 100% volunteer-led approach. Whenever feasible, leadership will be entrusted to the Bravehearts themselves or their families. Who could understand the CHD journey and its emotional and financial challenges better than the Bravehearts? All funds raised will be utilised directly for necessities, and every request will be evaluated impartially. We firmly believe that we shouldn't dictate what someone requires on their CHD journey; therefore, we remain flexible in the assistance and support we provide.



Income



BraveheartsNI functions solely through the dedication of volunteers, relying on the generosity of companies, organisations, and the wider community for our sustenance. During the fiscal year 2023/24, these sources accounted for 90.7% of our funding.

Additionally, we actively pursued external funding and grants, successfully securing 9.3% of our total income through these channels.

We extend our deepest gratitude to every individual and organisation whose contributions have enabled us to continue our essential mission. Your support plays a crucial role in allowing us to persist in our vital work, and we sincerely thank everyone who has made this ongoing effort possible.





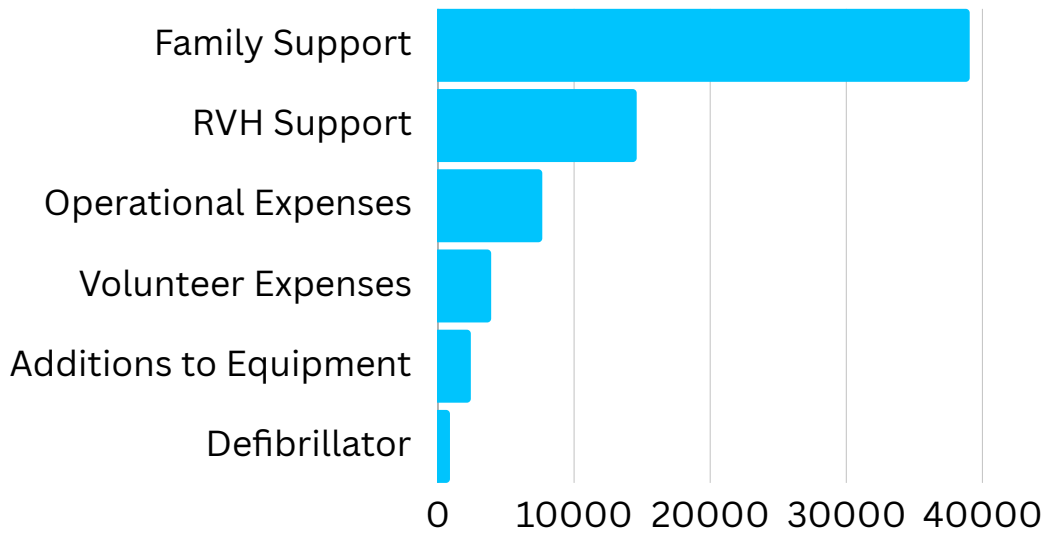
Individuals & Organisations

WE THANK YOU ALL!

from the bottom of our dicky little tickers



Expenditures



Family Support

Our Bravehearts and their families are at the heart of everything we do, we may be small but we have a mighty impact on those we help. Below are some of the ways we have supported our Bravehearts & their families over the past year.

HOSPITAL SUPPORT

we provided financial support for Bravehearts during hospital stays. Organise & pay for travel and accommodation for relatives when needed



ZOOM ACTIVITIES

remaining connected is important for wellbeing & a great way for our Bravehearts distributed throughout NI to conveniently meet regularly



COUNSELLING

49 sessions



EXERCISE

provision of both equipment & PT sessions with cardiac trained PT

WEIGHTED BLANKETS

provision of 21 weighted blankets, they are known to improve sleep & reduce anxiety



SUPERMARKET VOUCHERS

£4,394 in vouchers which were distributed to Braveheart families



HOODIES

provided Bravehearts with Hoodies & T-Shirts to help build our community & build a sense of inclusion



ENERGY SUPPORT

£1,001 electric top ups, gas payments & oil stamps

Expenditures Contd.

PERSONAL INDEPENDENCE PAYMENT

assistance to navigate this benefit, by offering guidance & completing forms. This is a free service to all Bravehearts



HOODIE BLANKETS

44 purchased & distributed to help keep our Bravehearts warm during the cost of living crisis



GROUP OUTING - FOOD FOLLOWED BY A VISIT TO THE THEATRE

We also had the pleasure of meeting the local award winning actor James Martin





OPERATIONAL EXPENSES

annually Bravehearts incurs operational costs which include insurance, storage for charity equipment, marketing materials, volunteer expenses, required memberships, stationery & postage

ACHD TEAM SUPPORT

Our commitment to supporting the ACHD Team remains unwavering. This year, we proudly sponsored an ACHD Education Day for Clinicians, provided funding for essential training software, and facilitated the attendance of three Consultants at a CHD Conference in London. Additionally, we co-organised & funded a transition day for our teenagers, ensuring continuity of care and support as they navigate this critical phase of their lives.



RVH SUPPORT - ADULT HOSPITAL

We support the Cardiac Wards on Level 5 who care for our Bravehearts, throughout the year we provided equipment and also basic essentials for the staff including tea & coffee.



RVH SUPPORT - CLARK CLINIC

We had the pleasure of providing Gillian the Play Specialist with craft items & toys to help entertain our younger Bravehearts during hospital stays & outpatient procedures. Also blankets and worry worms for made by our Crochet Together Group.



Expenditures Contd.... More of Our 2024



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Cash Handling

Cash & cheque donations are recorded in a receipt duplicate receipt book when received and lodged in the charity's bank account. The formality of the finance process is embedded and all completed with everything through an auditable process. The day to day administration is managed by the Chairperson and one of our Trustees. In order to ensure that all our financial transactions are fully within CCNI & HMRC compliance we use an Chartered Accountant to sign off our accounts ready for submission.

Recruiting

Building on the strong Braveheart Community we have already built, we had an incredible year welcoming new Bravehearts and their families. Unfortunately we mostly meet our new Bravehearts when they are going through the toughest times of their lives. It is testament to our hard work and attention to the Bravehearts and their families during this time that they feel compelled to help us with those in similar situations going forward. They are now embedded in our Community and not only have we given them purpose and a safety net during their lifelong condition, but it has also given the original BraveheartsNI Team a real sense of achievement knowing that our idea is still on the right path.

We continue to grow organically as the ACHD team contact us when they have a patient in need. We usually retain their support once we have helped them through their hard time as we have made such an impression. On the odd occasion that they don't, that is ok too, as volunteering isn't for everyone. Everyone travels a different path during their CHD journey.

This year we have had the pleasure of supporting new Bravehearts when they reached out to us for assistance with their Personal Independent Payment application.



Social Media

Social media is handled by a number of the Bravehearts. We have found this avenue to be the most effective form of communication so far. We have kept the administration of the social media sites to only a few Bravehearts in order to control content ensuring public compliance and conduct in accordance with charity commission rules.

Website

Websites was created in 2019 by one of our Braveheart Volunteers www.braveheartsni.com

The website continues to be managed in house.

Public Relations

Our Public relations have been very powerful from the beginning. The idea of a locally grown charity, our reasoning for existing and the fact that we are 100% volunteers with ALL monies staying within Northern Ireland has given us an advantage over bigger charities. We give our benefactors the opportunity to choose how they would like to see the money spent and were possible we will give them an update of what has been accomplished due to their generosity. Our public perception is one of commitment, drive, ownership and sustainability.

Plans for the Future

Our plans are to continue with the winning formula we have of being 100% volunteers. We keep all events manageable and involve the wider community in all our plans. Our focus is to continue to build our capacity while reaching out to as many Bravehearts and their families as possible across Northern Ireland. Our 'all inclusive' ethos is something we are particularly proud of. When and where possible we involve other charities and community groups in our event and fund raising as we believe that we must help each other. We are not territorial; we are willing to open our experience and events to others when we deem it mutually beneficial to do so.



Structure, Governance and Management



Trustees

All trustees give of their time freely and no remuneration or expenses were paid in the year. No trustee or person connected with a trustee received any benefit or subsidy.

Name	Appointment
Clare Caulfield	Chairperson
Stella Neeson	Trustee
Irwyn McKibbin	Trustee
Ann McKenna	Trustee
Daniel Pritchard	Trustee

Bankers

Santander, 131 Church Street, Ballymena, County Antrim. BT43 6DG

Governance

The governance of the charity is resolute but will remain a work-in-progress exercise for some time to ensure the appropriate level of support and guidance is purposeful to serve its members. The board members have put in place the regulatory, statutory and legal requirements for the charity to be deemed fit for purpose and will continue to evaluate and reassess in due course to remain current and competent in their charitable field. The Board's main effort to date is sourcing more sustainable avenues of funding, setting goals, targets and achievements for the subsequent year and putting in place a robust measuring process to track, monitor and evaluate the charity's annual activities, events and programmes. An ongoing task for the Board is putting in place procedures, process supplemented by the relevant policies.

Organisational Management

BraveheartsNI is a very hands-on charity, placing minimum emphasis on bureaucracy and boundaries. All members are strongly encouraged in unison to participate, interact and associate across all levels; which in turn, encourages empowerment and enables delegation for autonomous field working teams. The BraveheartsNI Chairperson/coordinator is responsible for the daily day to day control and coordination of the charity as an entity; however, should clarification be required for impromptu or unplanned matters, the coordinator will report directly to the board members for further advice or guidance. Leadership is devolved at a local level, whereby each event/activity leader is encouraged to take control and responsibility to exercise his/hers own management style and method for their specific event staging. BraveheartsNI are committed to developing their volunteer network be it personally or professionally and therefore employing such methodologies empowers the development of an individual's skills and abilities during every event to the utmost. During each process, BraveheartsNI will nominate and augment each event with a mentorship in the form of a subject matter expert be they; finance management, event management or human resource management to be on hand to offer expert advice, direction and guidance to each event leader before and during each event.

Planning

Creativity and innovation are always encouraged when an event, activity or presentation is at the earliest planning stage. BraveheartsNI encourage their associates to produce themes which are diverse to the norm. During the early planning stage, each event is scrutinized by the event leader who in turn reports to the BraveheartsNI coordinator, who jointly establish a comprehensive resource and support itinerary in the form of; human resources - event staffing, budget requirement/constraints, inventory of resources required to augment the event, legislation requirements - health & safety, medical and risk assessments, local police notification, goals aims and outcomes for the events and the list goes on. There will be a series of confirmatory meetings to measure the productivity, progress and efficiency leading up to the event. Prior to the event taking place, a final confirmatory meeting will take place whereby all those who will be in attendance at the event will attend including external stakeholders and providers to run through the sequence of events and scheduling for the event in question.



Activity Management

The fundamentals of activity management are safety first, raising awareness, fund-raising and time management. In doing so, each Braveheart associate, places these fundamentals at the centre of each project whilst carrying out any form of activity. The board and coordinator must be aware of what is happening within the charity and between the triangulation they can monitor progress and performance.

Motivation

Motivation goes a long way in binding the charity together. Appreciating the volunteers for their commitment and hard work goes towards gaining more future commitment. Hand-in-hand with motivation is defining and practicing effective time management. Since all BraveheartsNI associates give their time voluntarily, maintaining good time discipline is critical in order to avoid their charity commitment interfering with their personal lives. Throughout this reporting period, increased levels of motivation have been clearly visible from associates through continued commitment due to the charity, carrying out positive good news events and raising large sums of cash to support patients and family networks. Public reaction, support and benevolence have attributed greatly toward raising individual motivation and henceforth commitment. We made a new rule for the hardest working BHs in order to maintain energy and morale – No fund raising in January! Unless a family contacts us, January is rest, recuperation, and regrouping. We can thankfully say it's very welcome and much needed

Patients

Establishing contact with patients has grown greatly. We have to rely on our information being passed on within the hospital environment or one of our events being recognised by a Braveheart who will then get in touch. This is due to Data Protection. We continue to spend as little as possible on PR as the money would be better used elsewhere. This is a strategy which will continue to be analysed going forward.



Families

Connecting with families remains a gradual endeavor. Our means of communication primarily depend on the dissemination of information within the hospital setting or the recognition of our initiatives by a Braveheart who subsequently reaches out. This cautious approach is necessitated by Data Protection regulations. Notably, families are often hesitant to seek assistance, particularly regarding financial support. Consequently, we persist in relying on clinical staff to share our resources. Fortunately, our organic approach to fostering family connections is yielding results, albeit at a measured pace.

Volunteers

Our volunteers are mostly Bravehearts themselves. The initial teams from conception of the charity have proven to be exceptional. They work, have families and have major restrictions on their health; however they give all their free time to making BraveheartsNI the success as we know it. Their deep connection to the charity is rooted in the personal sacrifices they've made, reflecting a profound pride and bond with its mission.

Risk Management

Every event is managed to the highest ability. Individually run events which we have no knowledge of but the funds are donated to BraveheartsNI are out of our control. However, any event we have been directly involved with or work with a partner with have had any risks identified and planned for accordingly.

Managing External Relationships

BraveheartsNI have gained a very personal relationship with most of our benefactors. As the Bravehearts themselves attend all events the partner will get first-hand knowledge and updates of what their donations were used for. This has fostered a very beneficial referral relationship as very early on in our process we have benefited from workplaces referring us to other organisations encouraging their support as they were very impressed at the personal nature of our purpose. We have built incredibly strong relationships with other charities such as HeartbeatNI where we marry up events and refer CHD patients to each other. We have very distinct purposes and can see the benefits in working together. These unions have been very successful.





Review of Activities and Achievements

Our events aimed not only to generate funds but also to increase awareness, a goal swiftly achieved as numerous local businesses enthusiastically joined us in spreading the word about our mission and how others could contribute. These relationships will be nurtured in the years ahead, with efforts focused on maximising their potential impact.

Future Intentions

We intend to continue along the path we are currently travelling. It has been a success thus far with a formula which is fluid and continues to grow to meet all future challenges. We will require flexibility and autonomy to meet the ever changing needs of our Bravehearts and their life circumstances as they grow older. We will endeavor to push for a designated ACHD unit and assist the medical teams with equipment or resources not readily available from the NHS. We will continue to grow our volunteer base encouraging the Bravehearts and their families to take part in and ownership of the charity as our moto will always be

'For the Bravehearts by the Bravehearts'.



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