

Trustees Annual Report for year ending 31 March 2023



Executive Summary



We had another remarkable year of connection and friendship. Due to the nature of our purpose, it was also another year of loss and sadness with the passing of Bravehearts who had become our family. It is in their memory that we continue to grow and spread our charitable work within our Bravehearts community.

BraveheartsNI continues to be 100% volunteer led with a core of volunteers and public supporters who drive us forward. We have been humbled this past year with the outreach of companies such as Ballylumford Power station, Blackstone Bar, Various local football teams, Kings of the Road Truckers and community groups who have chosen us as their partner, mostly because they see the incredible work we do and the change we make in lives and families, but also because we are 100% volunteers, with all our income being spent where it is needed most within our Braveheart community in Northern Ireland.

This past year we had a great many initiatives. 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 doubled in size with bundles of beautiful blankets delivered to various care homes and Children Clark Clinic, RVH, Belfast. Hundreds of tiny hats for premature babies are constantly crocheted and gifted to Special care units around the country.

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 year of supporting our Clinicians and cardiac wards in RVH. We sponsored our clinicians to be able to attend training courses in GB. We also provided them with MacBooks and online learning technology to advance their knowledge and enable them to teach all things CHD to other medics around the country. We provided ice machines to all the wards who house our Bravehearts when they are admitted.

30 of us had a wonderful day at the Christmas Panto in Belfast with a buffet in the Europa hotel sponsored by a local business. New friendships and connections were made within the group which is exactly what we set out to do.

We continued to help many families, we often can't talk about this support as it's a very personal situation and the families welcome the respect of privacy.

We funded 2 wheelchairs to help ease the struggle of our Bravehearts, who got a new lease of freedom having the chair to rely on.

The very nature of who we support means that there are tough times amongst the joy. We grieved the passing of our fabulous volunteer Loraine (Rainer). These times serve as a very unwelcome reminder of the reality of the conditions our Bravehearts live with.

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) impacts nearly 1 in 100 babies born in the UK, with 1 in 4 requiring surgical interventions and lifelong care. Over the past 30 years, the outlook for individuals with CHD has drastically improved, with the survival rate increasing from 20% to 90%.

The severity of these cardiac defects varies, leading to unique challenges for each individual. While some can lead normal lives, others face 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.

The unfortunate reality is that many individuals affected by CHD have their lives cut short.

Lorraine 'Rainer' Donnelly

9th November 1977 - September 2022



On the 2nd September 2022 our dear friend and Braveheart Lorraine passed away peacefully in the RVH, Belfast. Lorraine (or Rainer as she was known to most!) never let her complex CHD health get in her way of achieving her personal or academic goals. Lorraine attained a distinction in her Masters Degree & had a paper published on CHD & how it impacted mental health, prior to this there had not been much consideration or research given to this important topic.

Rainer wore many hats daughter, sister, wife, auntie and a wonderful friend to many, always offering a listening ear accompanied with compassion, empathy & wisdom. Her entire adult life was dedicate to others through her much loved work as a Counsellor.

Lorraine was a highly respected volunteer within the BraveheartsNI Community, her experience was integral to many successful funding bids through her professional insight into how CHD impacted us psychologically.

We continue to keep her husband Connor, parents, siblings, nieces & nephews & wider family circle in our thoughts.

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

Overview

BraveheartsNI is a local 100% volunteer led charity supporting teenagers and adults in Northern Ireland living with Congenital Heart Disease (CHD). BraveheartsNI has recently just completed its ninth year and what a wonderful year it has been with many ups and downs!

We continued to welcome many new Bravehearts into our growing community along with their families and friends. We became bigger and busier than we could have ever imagined. This year had some sad times with the loss of some of our lovely Bravehearts, at times like this we try to focus on positives and were blessed to be able to support these Bravehearts and their families.

The support we were able to offer to our Bravehearts varied depending on the needs of the individual and their family. Some of the support included financial support during hospital stays, provision exercise equipment & PT sessions, weighted blankets, hoodie blankets, financial support for food & energy, wheelchairs name but a few.

The highlight gathering of the year was when we went to the pantomime Cinderella in January 2022.

We remained dedicated to successfully assisting Bravehearts with their Personal Independent Payment applications.

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 continue to build a network of peer to peer support for CHD patients living in Northern Ireland with responsibility being assumed by the Bravehearts themselves. All work through BraveheartsNI continues to be completed on a 100% volunteer basis with all funds raised or donated being used directly where needed within NI. The Bravehearts themselves are gaining strength and friendship by working alongside each other supporting and encouraging themselves and others in their efforts to reach other Bravehearts and their families. This is making huge strides in combating isolation within this small demographic group and is giving our Bravehearts a purpose, one that they can control and develop. Remaining a volunteer patient led charity is of the utmost importance to us. We have already built an extremely strong ethos and have been rewarded for this by support and donations.



Ethos

At BraveheartsNI we have shaped and enshrined an all-encompassing people focused culture based on our inherent values of compassion, benevolence and willingness to help others, creating synergies which jell the team together to produce effective results. We have placed people as our key element and empower through responsibility across all functions. By doing so, we value the work of our volunteers, make them feel part of the team whilst affording them to have autonomy to work on initiatives and manage collective based activities on our behalf. We provide training and education to ensure our teams recognise and agree the importance of our need, supporting teenagers and young adults with CHD. As our culture is defined through need, we pride ourselves on being approachable, welcoming and open-minded to provide support mechanisms. We encourage and engage with open communication, like to consult with all our team/s and welcome feedback and commentary across all levels.

Strategy

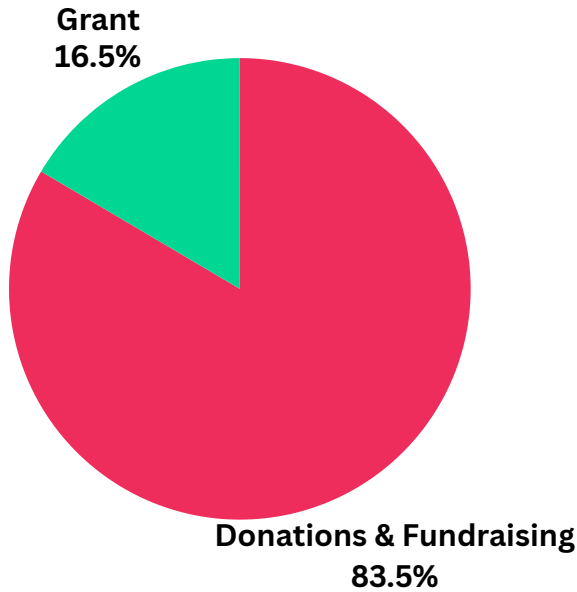
Our strategy has been fluid from the start due to the nature of CHD. No two Bravehearts or their support networks are exactly the same in their needs and everyone deserves a chance to get help and support tailored to their needs. As time progresses we will identify reoccurring issues and areas of need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

Policy

It was always our policy from conception that we will remain 100% volunteer led. We will, where possible be led by the Bravehearts themselves or their family. Who better to know the CHD journey and the emotional and financial worries of this than the Bravehearts themselves? All monies raised will be used directly where it's needed, and every request will be considered without prejudice. We believe that we are not in a position to be able to dictate what a person needs on their CHD journey, and as such we need to remain fluid in the help and support we offer.



Income



BraveheartsNI operates as a charity entirely led by volunteers, and our sustenance is reliant on the benevolence of companies, organisations, and the general public. In the fiscal year 2022/23, this support accounted for 83.5% of our funding.

Additionally, we actively pursued external funding/grants, achieving success in securing 16.5% of our total income through these avenues.

We express our sincere gratitude to every individual and organisation whose contributions have enabled us to persist in our crucial mission. Your support is instrumental in allowing us to carry on with our vital work, and we extend heartfelt thanks to all who have made this ongoing effort possible.



EP Ballylumford



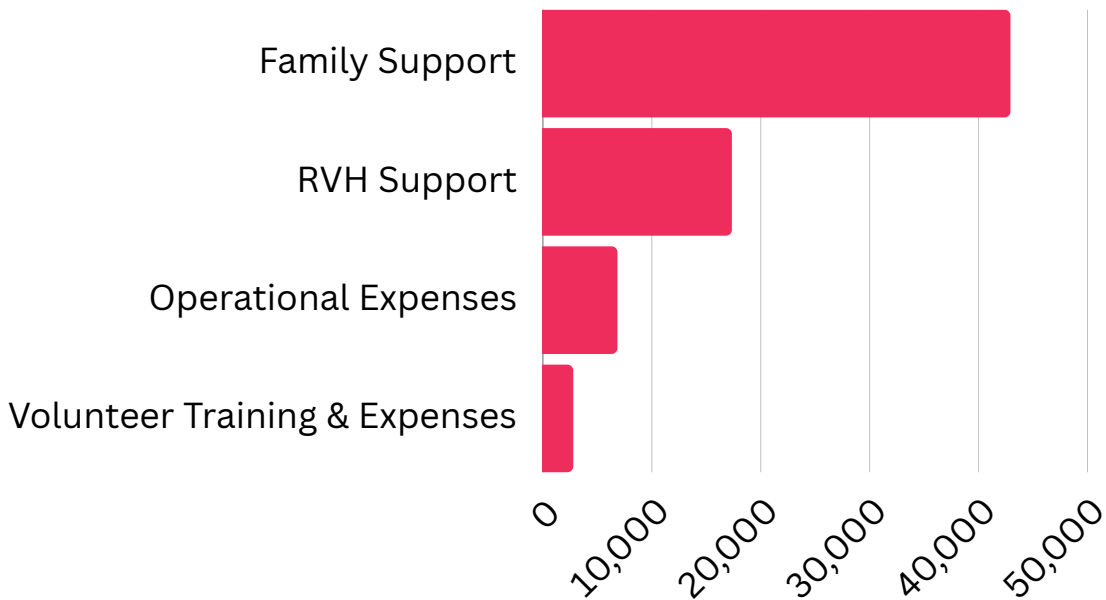
Individuals & Organisations

WE THANK YOU!

from the bottom of our dickey 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.

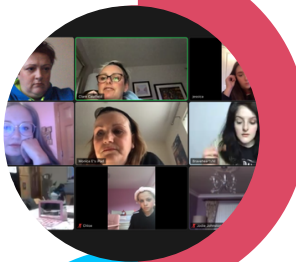
HOSPITAL SUPPORT

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

212 sessions
23% increase on 2021-22



EXERCISE

provision of both equipment & PT sessions with cardiac trained PT

WEIGHTED BLANKETS

provision of 14 weighted blankets, they are known to improve sleep & reduce anxiety



SUPERMARKET VOUCHERS

£5,227 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

£1,149 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

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



WHEELCHAIRS

1 powerchair & 1 wheelchair
These were requested by the ACHD Team to enable the users to remain independent



GROUP OUTING TO THE THEATRE FOLLOWED BY FOOD





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

We are dedicated to supporting the ACHD Team and this year we were able to provide MacBooks, software used for training and fund 3 Consultants to attend a CHD Conference in London.



RVH SUPPORT - ADULT HOSPITAL

We support the Cardiac Wards on Level 5 who care for our Bravehearts, we provided each of the wards with an ice machine & toiletries for patients. There was 2 additional media cabinets complete with a console, television, games & DVD's supplied



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



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

Establishing contact with families is still a slow process. 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 have found that families are very very reticent at asking for help, especially financial help. We continue to rely on the Clinical staff passing on our information. Thankfully the organic model of building family contact is paying off albeit slowly.

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. They have a pride and bond with the charity as they themselves have put everything into it despite their hardships.

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.



