

# ECHO

## Impact Report 2018

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Our mission is to make a difference to the lives of heart children and their families.



# Introduction

## Hello from Samantha, Chief Executive

I want to start this report by thanking each and every one of our supporters and volunteers for the difference they have made to the lives of children with heart conditions and their families, as we reflect on our impact in 2018.

### Here are some of the ECHO highlights from 2018:

- Welcoming 220 new parents to ECHO who needed emotional, practical or social support, plus their children and extended families
- Providing 148 parents with a bespoke ECHO cardiac antenatal class for parents whose baby has been diagnosed with a heart condition during pregnancy
- Continuing for the third year to provide vital support from our dedicated cardiac support worker to cardiac families in hospital, at home and in the community
- Launching our first Teen Hub events specifically for heart teens aged 11-17 to meet others with heart conditions and feel more confident as they transition to adult services

We are looking forward to supporting more families, as our membership is growing and we continue to support children, parents and their extended families.

We have continued to support families within the Evelina London Children's Hospital networks who are not members with our softer support such as our toy chest, resources for families, care bags, cardiac family support worker and our ward visits and events.

Once again I want to thank our members, volunteers and supporters - you work with our small team to achieve so much.

I love meeting people linked to ECHO who believe in our vision: *"A world where the emotional, social, financial and medical needs of heart families are met."* With your help, we will continue to work hard trying to get closer to our vision.



**Samantha Johnson**  
Chief Executive, ECHO  
[samantha@echo-uk.org](mailto:samantha@echo-uk.org)

# Who we are

**At ECHO, we know that discovering your child has a potentially life threatening heart condition is one of the hardest things any parent can hear. Many families find it difficult to cope and welcome additional support, which is why ECHO exists.**

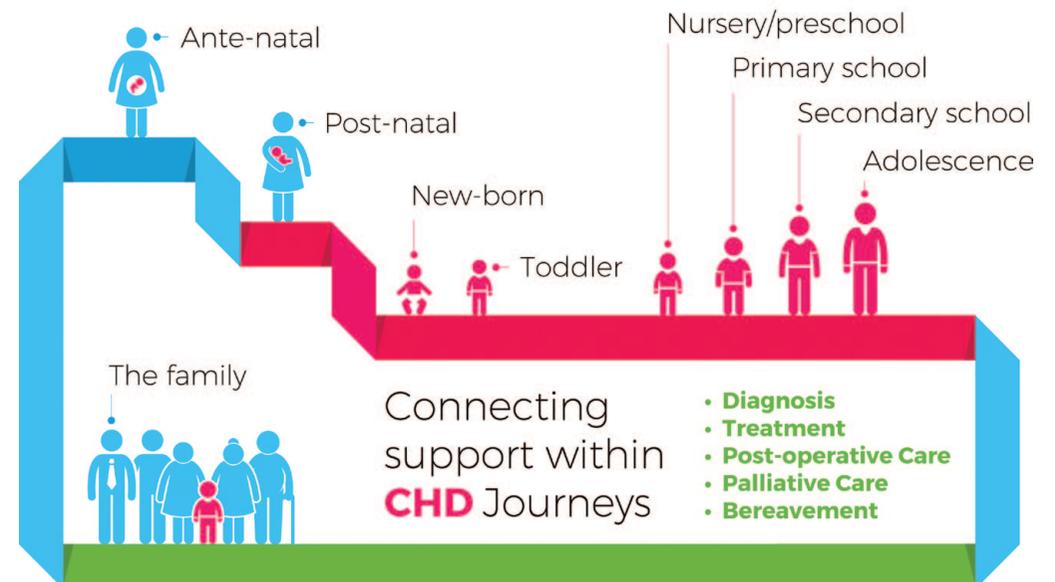
ECHO supports children with heart conditions and their families at every stage of their heart journey, helping from diagnosis (often during pregnancy) through to a child's teenage years and beyond as they transition to adult cardiology services.

We provide practical and emotional support by: welcoming new families arriving at the Evelina London and providing essentials; funding a specialist cardiac antenatal class; organising heart community events; connecting heart parents with other parents and medical professionals; funding a dedicated Cardiac Support Worker for families in the hospital and community and providing opportunities or heart teens to meet and make friends.

ECHO connects the children's heart community by bringing together children and young people with heart conditions, their families and medical professionals.

ECHO is regarded by many as a second family and a strong network to be part of at all life stages of the CHD journey.

Often people access support in a crisis and again years later at different milestones.



# Who needs us?

## Professionals

We have built and maintained strong relationships with medical, nursing and professional teams within Evelina London networks. We work with clinical staff to support in coordinating events, supporting families and providing resources to the hospital.

## Siblings

Having a sibling with a heart condition can be tough so siblings living with a heart child are also supported from birth to 19. Siblings are welcome to all our family events and we support them in any way they need.

## Parents and carers

From prenatal diagnosis, throughout their child's life, or whenever they need our services, we provide continuous support to parents and carers.



## Children and Young People

We know how vital continued support is throughout the lives of children with heart conditions, at every age, so we support children and young people at every stage of their heart journey.

## Wider family and friends

Fostering understanding of what heart families are going through is crucial for sustainably extending support networks amongst wider family and friends of ECHO members.

# 2018 highlights

**We are delighted to have achieved so much to support the ECHO heart community in the past 12 months, here are some of our key moments:**



**We received funding from Children In Need to run 3 years of our ECHO Teens programme**, specifically a series of focused hub workshops and fun outings for heart teens. The sessions include advice and information about living with a heart condition and wellbeing and lifestyle sessions such as diet, exercise, stress and anxiety alongside fun activities enabling young people to meet others their age with heart conditions, and explore new challenges. We held our first hub in March 2018 with a get to know each other day out at Southbank Food Market, and 20 teens explored Margate.



We were delighted to be chosen by the NatWest Corporate & Commercial Banking team as their charity of the year for 2018-2019, and **so far they have raised over £50,000 to fund vital services for heart children and their families**. ECHO was nominated by the team for the prestigious Perrys Exceptional award, which recognizes inspirational charities, individuals and businesses across the country.



We launched our **Walking In Our Shoes project, a community for dads and male carers** to create and join local walking groups, to help relieve stress, tackle depression and give heart dads a chance to exercise while connecting with others and talking in a relaxed setting. For the launch, we created a short film which hears from a group of ECHO dads about their experiences.

# 2018 highlights



We held a **community day for bereaved parents**, dedicated to giving bereaved parents, grandparents and siblings the chance to meet with each other and the ECHO team to talk, reminisce, share special memories and, if needed, lean on one other for comfort and support.

*ECHO sponsors our very own reflection space and bench within Lambeth Palace Gardens. This special space is situated within a beautiful spot and offers the perfect get away from the hospital when some peace, quiet and fresh air is needed. Our reflection bench is also often a focal point at our annual remembrance gatherings for bereaved parents and families, and we encourage families who have lost a loved one to visit the bench whenever they wish.*



We held the first ever **Valentine's Super Social** at the Evelina London as part of National Heart Month: a party for families with a magic show and crafts, and the opportunity for families to write letters to Evelina staff who have helped them at the hospital.



We were delighted that almost **500 of our members attended our Festive Tropicana Christmas Party**, held at Millwall Football Club, for a fun and festive day of games, music, a choir, dance, food and crafts – and of course a visit from Mr Claus himself! Researchers from King's College London joined us to show heart families their latest technology in 3D heart imagery, which children and families could explore using a futuristic Virtual Reality headset.

# 2018 in numbers

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**New parents welcomed to ECHO**



**Online support group members**



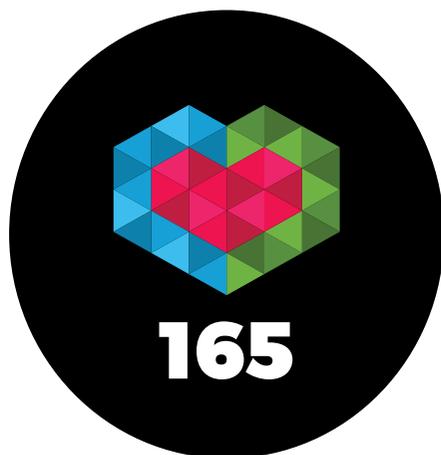
**Events held**



**Volunteer hours given**

# 2018 in numbers

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**Heart teens and siblings who attended events**



**Fantastic ECHO fundraising individuals**



**Total income**



**Parents attended the ECHO antenatal class**

# Emma's Story

**At their routine antenatal check at 21 weeks, Emma and Bruce discovered that their unborn son had a life threatening heart condition and would need critical care from the moment he was born.**

Mum Emma recalls learning of the diagnosis, and the moment that changed her life forever: *"Hearing those words and knowing that Liam was, and would be so ill, was gut-wrenching. I was just in complete shock."*

The remainder of the pregnancy was, as to be expected, a far more anxious and unsettling time for the family, but with support from ECHO and the medical team around them, stresses were able to be managed and alleviated somewhat, as Emma explains:

*"Very soon after we learnt of Liam's diagnosis, we were introduced to ECHO, and we were brilliantly supported through their amazing network. Because of ECHO, we never felt alone. ECHO helped hugely in helping us to sustain and maintain a family life in the early days when things were the darkest."*

Little Liam was born in December 2008 with the complex congenital heart condition called Transposition of the Great Arteries, requiring surgery and time to recover which the family spent staying in Ronald McDonald House: *"It was confusing and hard for his brother. One day Ethan came to visit Liam in hospital. He didn't understand why he was so ill and he tried to pick him up off his bed and carry him home."*

Liam had the Arterial Switch operation, and today he enjoys living life as any regular ten year old boy would. He is part of his school's running club and a keen and active member of the local Cubs. He is very close with his brother Ethan, and they love to play together and go on those adventures that Ethan dreamed about.

Emma explains: *"Liam is doing really well. It is sometimes hard to see him as someone with a very serious heart condition. He is stable and as a family we are no longer living in such trauma, but it is never far from our minds. I know that ECHO will be with us for life, throughout life, and knowing that Liam can be part of their Teens Club soon gives me such gratitude."*



# Claire's Story

**“The ECHO antenatal day gave me so much hope and inspired me to become a volunteer later on.”**

*My name is Claire and I have been volunteering for ECHO for over 7 and a half years.*

*When I was pregnant with my son Oliver I found life incredibly hard. The antenatal day gave me so much hope and inspired me to become a volunteer later on.*

*My son was one when I did my first antenatal talk. Still raw from my experience of operations and hospital trips, my talk was emotional but so rewarding.*

*From then on I helped out on ward visits, coffee afternoons, the Christmas party and transition days. Sometimes on ward visits I saw people I had seen at the antenatal talks and to see them with their babies was just wonderful. They remembered me and asked after Oliver and told me how my antenatal talk had helped them through a difficult time.*

*Talking through my journey; pregnancy, operations, Oliver's development and to where we are today, makes me realise how far we've come as a family.*

*I always tell our new members that we're not unlucky, we are the luckiest family to have this little boy in our lives. He has changed our lives in so many ways, as have ECHO.*

*I am proud to be part of this organisation and hope to continue to be part of it for many years to come.*



# We couldn't do it without you

## Individuals

Last year, over 1,600 individuals supported ECHO by donating to appeals and taking on fundraising adventures and challenges – including sponsored haircuts, tuck shops, pub quizzes and more. We also received support from over 90 individual fundraising pages. You held pub quizzes, trekked Costa Rica, joined team ECHO at the London and Brighton marathons, bungee jumped, zip-lined and more...and we couldn't be more thankful.

## Corporate fundraising

We are so grateful for the corporate organisations who have made such an impact with their support in 2018. The NatWest Corporate & Commercial Banking team have been fundraising for us in 2018, since choosing to support ECHO as their charity partner. The team have held gala dinners, bowling trips, clay-pigeon shooting challenges and more, all in aid of heart children.

## Volunteers

We would be unable to reach the number of heart families and provide the support we do without our dedicated volunteers. Our volunteers donated over 1,700 combined hours of their time, working in our office on fundraising, communications and impact measurement; helping to run and plan community events; visiting heart parents staying in hospital during their child's treatment; speaking to newly diagnosed heart parents at antenatal classes, fundraising at tube stations and football clubs and volunteering in a medical capacity. Thank you to everyone who has given their time to support ECHO!

Our volunteers gave the equivalent of just under £20,000 in their time (based on London Living Wage).

## Schools

ECHO is supported by many schools across the UK, who hold fundraising events and awareness days throughout the year, in particular during National Heart Month in February. We want to thank all the schools who got involved this past year!

## Events

Our inspirational supporters took on epic challenges for ECHO in 2018, including the Evelina London Children's Hospital team who cycled across Costa Rica, the teens who bungee jumped, the zip-lining hospital staff and volunteers, and our marathon runners in London and Brighton.



# We couldn't do it without you

## Organisations

In recent years Rory's Heartbeat have continuously raised money for ECHO and organised several donations such as the Easter Egg Campaign this year to sponsor eggs or books to children who are in hospital at Easter time. This makes such a difference for children and their families who are currently going through a hard time at hospital.

We were also delighted in 2018 to be chosen as one of Tesco's Bags of Help scheme charities, and be part of the Co-op Community Fund whereby a percentage of customers' shop is donated to ECHO. Thank you to everyone who chose to support ECHO at the Co-op.

## Trusts and foundations

We are grateful to all the trust and foundations who generously supported our work including:

- Whitehead Monkton
- Haslers Foundation
- Annadale Trust
- British Science Museum
- Syder Foundation
- Clara E Burgess Charity Trust
- People's Postcode Lottery



# How you can help

## Discovering your child has a potentially life threatening heart condition is one of the hardest things any parent can hear.

Children with heart conditions often face an uncertain future, where medical tests and treatment become normality. Many families find it difficult to cope and welcome additional support – which is where ECHO comes in.

### Your support makes our work possible.

**Donate:** Your donation could help provide a comfort pack to parents arriving at Evelina; help us run community events to bring families together and share information; fund our Cardiac Support Worker to visit families, and much more.

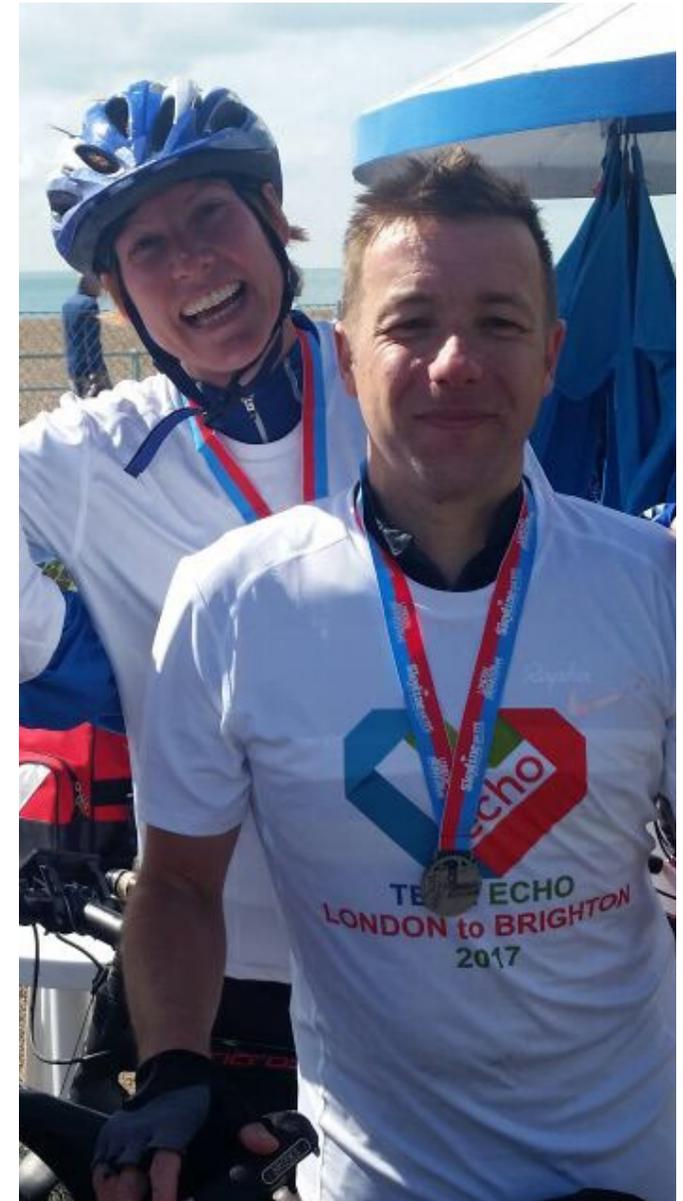
**Fundraise:** There are lots of great ways to fundraise from sponsored walks to office raffles, cake sales to once-in-a-lifetime travel challenges. You can even create your very own bespoke fundraiser!

**Volunteer:** Our volunteers are essential to everything we do – we simply could not support the ECHO community without them. We advertise roles on our website but you can also get in touch to find out other ways you can give your time to support heart families.

## Get in Touch

[hello@echo-uk.org](mailto:hello@echo-uk.org) | [www.echo-uk.org](http://www.echo-uk.org) | [f](#) [t](#) [i](#) @echoukcharity

ECHO, Canterbury House, 1 Royal Street London SE1 7LL.  
ECHO is a Registered Charity No. 1146494



# How you can help



"I love being able to take part in fundraising events. We've held cake sales and done lots of running - my mum and brother Will have completed a sponsored 5km run and my Uncle Rob did a 10km race too. All my siblings and cousins ran a 1km race with me as well!"

**James - ECHO Teen member & heart patient**

## What difference can you make?

### **£12 gives**

A comfort pack for families arriving at hospital by ambulance, empty-handed having had zero time to pack.

### **£25 gives**

Specialist play equipment for children being treated in hospital.

### **£45 gives**

Sponsors an ECHO gathering for families, providing solace as well as practical information.

### **£90 gives**

Vital 1:1 support to families in crisis.

# Looking forward in 2019



## In 2019, we look to:

- Develop support for teens by continuing our ECHO teens hub events, offering teens an opportunity to learn about issues around health and wellbeing as well as their transition to adult cardiology services, while meeting other heart teens and offering opportunities to explore fun days out.
- Focus more energy on wellbeing, developing from feedback from our 2018 community days and previous events. We will hold two wellbeing days for heart patients, parents, carers and family to take time to learn about their own wellness and develop techniques in mindfulness as well as complete an introduction to first aid for babies and children.
- Continue to be part of the conversation around the landscape of changes within the cardiology service delivery, and to best represent our members in any way we can.
- Continue to campaign and advocate on behalf of our members, following on from our successful campaign for improvements to the government's DLA provision and information provided to assessors.
- Endeavor to raise more funds to continue our work in the heart community and to be able to support even more families needing support.
- Connect with our members through a postal newsletter, re-establishing engagement post-GDPR.

# Trustee report



## Staff

The ECHO team is made up of Samantha Johnson, Siobhan Morton, Emma Orpin and Sinéad Houlihan with support from a sessional youth team, Tania & Michelle who help us to provide our ECHO Teens Hub and Transition service to young people. ECHO's Cardiac Family Support Worker changed and we welcomed Vicki to the team as Cardiac Family Support Worker - a joint role co-funded by the Rainbow Trust Charity.

## Spaces

Our office space, family room and meeting space have been used by ECHO members, some have used the space whilst waiting for children's surgery, including parents of a child who stayed in hospital for over 8 months. Our room offered some respite, a space for others to complete DLA applications, housing forms or to meet with the ECHO Team. We have also used the office space to run siblings art clubs in the space and teenage and bereavement support sessions.

We provided equipment and furniture to the parent's room and playroom at the Evelina London Children's Hospital and are discussing how we can support the move of the cardiac services within the Evelina London Children's Hospital - including fetal cardiology, cardiology and PICU.

## Financial Review

ECHO worked hard to raise funds needed to support members, we have diversified our income stream and apply to trusts, foundations and companies to support us as well as working with individuals to raise money. It hasn't been easy; the charity sector experienced some negative press and we needed to work extra hard building relationships with people and getting our message heard.

Our board worked with the CEO and team to deliver excellent services to heart families when they need us and ensured we are able to grow for the future development of ECHO. The need for our services has grown as has the

need for volunteers and donations.

In 2019 ECHO will create our next 3-5 year strategy, with emphasis on the financial stability, supporting the Evelina Networks and how we grow to best support the needs of members across London and the country to ensure the services we provide continues.

ECHO are proud to announce that the Cardiac Music Therapy pilot project has been a great success. Our investment in Cathy the therapist and the musical instruments has enabled ECHO to help 80 children and their families as they go through difficult medical procedures.

With staff at the Evelina London Children's Hospital supporting the need for the service, it has taken three years to gather sufficient evidence for the hospital to allocate a budget for Music Therapy. ECHO have funded the post from inception to the point where the hospital could take over, and are very proud to have played an instrumental role in the introduction of this wonderful service.

## Structure, Governance and Management

The charity is a private company limited by guarantee (company number 7867592). The company was incorporated on 1 December 2011 (as amended by special resolution registered at Companies House on 6 March 2012) and registered as a charity on 21 March 2012. The company was established under a Memorandum of Association which established the objects and powers of the charitable company and is governed under its Articles of Association.

## Recruitment and appointment of trustee directors

The directors of the company are also charity trustees for the purposes of charity law. Under the requirements of the Memorandum and Articles of Association the trustee directors must retire at the first Annual General Meeting (AGM) and subsequently each trustee director may be elected to serve for a period of three years after which

they must be re-elected at the next AGM. The minimum number of trustee directors is 5 and there is no maximum. The trustee directors can be appointed in general meeting or by the other directors. Questions arising at a meeting shall be decided by majority votes. The trustee directors are responsible for the general control and management of the charity. They give their time freely and receive no remuneration or other benefits. Any expenses reclaimed from the charity are set out in the accounts. The trustees meet approximately every 12 weeks and are responsible for decisions made in relation to the running of the charity. Members of the committee may join alternate meetings. Any trustee director may call a meeting of the trustee directors provided reasonable notice is given.

## Risk management

The trustee directors have assessed the risks the charity faces and has put in place policies to manage the risks. For example, the charity has plans in place to protect against a downturn in the level of our income, finances are kept under review, Disclosure and Barring Service (DBS) checks are made, all members of staff have a contract of employment and comprehensive staff handbook which outlines all terms and conditions of employment and staff and volunteers working directly with children, young people or vulnerable adults are DBS checked.

## Declaration

The trustee directors declare that they have approved the trustee directors' report above.

Signed on behalf of the charity's trustee directors:

## David Philpott

Chair of Trustees

# Trustee report

## **Charity name**

Evelina Children's Heart Organisation  
Limited

## **Working name**

ECHO

## **Charity registration number**

1146494

## **Company number**

7867592

## **Registered Office**

Canterbury House,  
1 Royal Street,  
London,  
SE1 7LL

## **Board of Trustee Directors**

### **Chair**

David Philpott

### **Trustees**

James Pincus  
Patricia Jane Ward  
Alex Bicknell  
Joanna Eyeson  
Mark Kennor (until 31 Jul 2018)  
Stephen Wood  
Marc Harry

## **Staff**

### **Chief Executive**

Samantha Johnson

### **Community & Administration Manager**

Emma Orpin

### **Volunteering & Communications Manager**

Siobhan Morton

### **Communications & Volunteering Coordinator**

Sinéad Houlihan (started 17th Sep 2018)

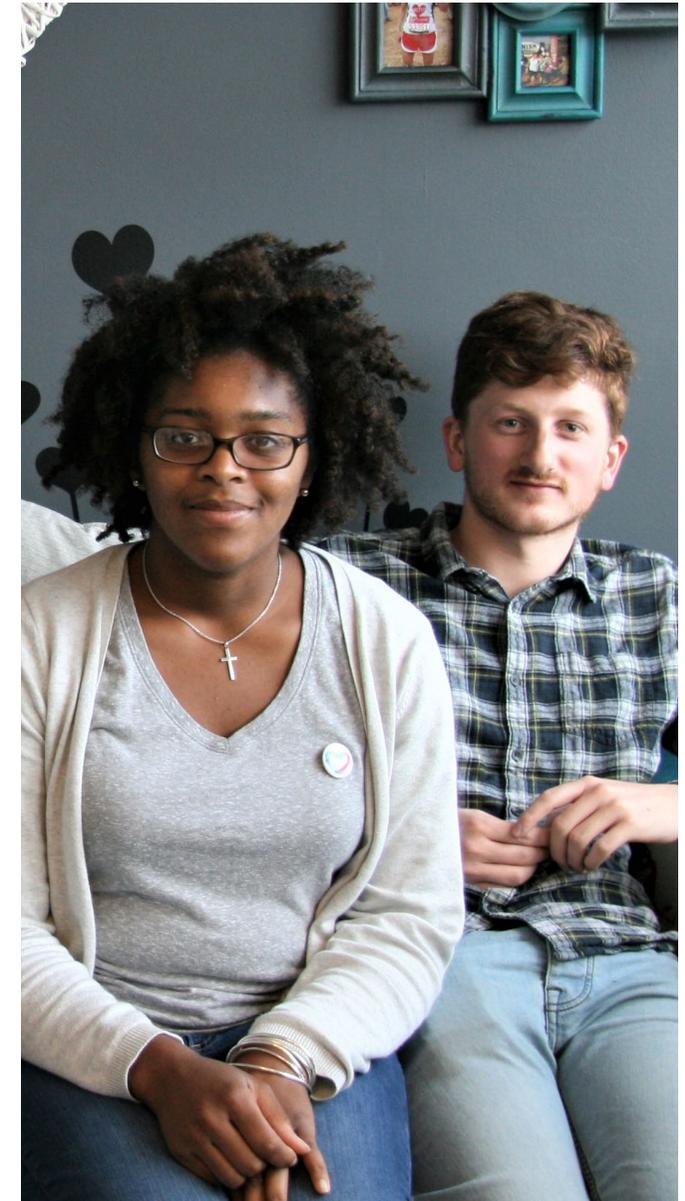
## **Independent Accountant**

Drive Business Services  
52 Crown Drive,  
Inverness,  
IV2 3QG

## **Bank**

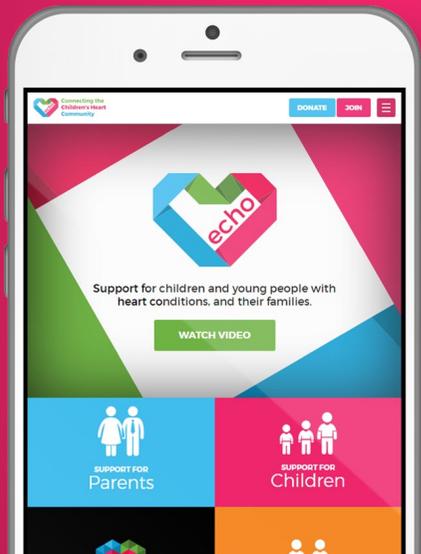
CAF Bank  
25 Kings Hill Avenue,  
Kings Hill,  
West Malling,  
Kent,  
ME19 4JQ

Accounts for the period from 1 January 2018  
to 31 December 2018.



# CONNECTING THE CHILDREN'S HEART COMMUNITY

For more information on joining ECHO and receiving support, or to find out how you can support us by volunteering or fundraising, head to: [echo-uk.org](http://echo-uk.org)



## GET IN TOUCH

**Call:** 020 7998 4710  
**Email:** [hello@echo-uk.org](mailto:hello@echo-uk.org)  
**Visit:** [www.echo-uk.org](http://www.echo-uk.org)  
**Follow:** [f](https://www.facebook.com/echocharity) [i](https://www.instagram.com/echocharity) [t](https://www.tiktok.com/@echocharity) @echoukcharity