

EVELINA CHILDREN'S HEART ORGANISATION LIMITED

England & Wales · Charity number 1146494

Details

Other names ECHO

Status Registered

Legal form Charitable company

Company number [07867592](#)

Registered 2012-03-21

Register [View on the Charity Commission register](#)

Contact

Address Evelina Children's Heart Organisati
Canterbury House
1 Royal Street
London
SE1 7LL

Phone 02079984710

Email hello@echo-uk.org

Website www.echo-uk.org

Activities

Objects: TO RELIEVE CHILDREN WHO ARE SICK, CONVALESCENT, HANDICAPPED OR DISABLED, PRINCIPALLY FROM HEART DISORDERS AND WHO ARE EITHER PATIENTS OR FORMER PATIENTS OF THE EVELINA CHILDREN'S HOSPITAL WITHIN GUY'S AND ST THOMAS HOSPITAL TRUST, OR WHO ARE RECEIVING TREATMENT AT CLINICS VISITED BY THE TRUST PAEDIATRIC CARDIOLOGISTS, BY PROVIDING INFORMATION, FRIENDSHIP, MORAL SUPPORT, EQUIPMENT TO THE HOSPITALS OR SUCH OTHER ACTIVITIES AS THE TRUSTEES DEEM FIT FOR THE CHILDREN AND THEIR PARENTS AND CARERS.

Activities: SUPPORTS CHILDREN TREATED AT THE EVELINA CHILDREN'S HOSPITAL (AND CLINICS VISITED BY EVELINA CARDIOLOGISTS), PRINCIPALLY FOR CONGENITAL HEART DEFECTS, AS WELL AS THEIR PARENTS/CARERS/CLOSE FAMILY. PROVIDE INFORMATION, FRIENDSHIP, SUPPORT WHEN PARENTS FEEL ALONE OR NEED ADVICE. ADVOCACY PROVIDES PATIENT VOICE TO HELP GUYS & ST THOMAS'S NHS TRUST SHAPE SERVICES FOR CHD.

Classification

- **How:** Makes Grants To Organisations, Provides Advocacy/advice/information, Other Charitable Activities
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Other Defined Groups

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£332,364	£463,069	-	-
2023-12-31	£325,074	£355,689	-	-
2022-12-31	£283,626	£280,368	-	-
2021-12-31	£290,215	£218,423	-	-
2020-12-31	£382,363	£176,890	-	-

Trustees

Name	Role	Appointed
Stephen John Wood	Chair	2017-07-19
JAMES PINCUS		2024-05-08
Joanna Eyeson		2014-05-01
Karan Singh Panesar		2026-02-16
Marc Andrew Harry		2017-10-25
PATRICIA JANE WARD		2012-04-26

EVELINA CHILDREN'S HEART ORGANISATION LIMITED

England & Wales - Charity number 1146494

Accounts



EVELINA CHILDREN'S HEART ORGANISATION LIMITED

(A Company Limited by Guarantee)

Registered Charity Number 1146494

Company Number 7867592

REPORT OF THE BOARD OF TRUSTEE DIRECTORS

FOR THE PERIOD 1 JANUARY 2024 TO 31 DECEMBER 2024

Evelina Children's Heart Organisation Limited

(A company limited by guarantee)

Report of the Board of Trustee Directors for the Period 1 January 2024 to 31 December 2024

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 Stephen Wood

Treasurer Alex Bicknell

Trustees

- Alex Bicknell
- Joanna Eyeson
- Stephen Wood
- Marc Harry
- Jane Ward
- James Pincus Joined 8th May 2024
- Lynne Powrie resigned 26th April 2024

Special Advisors to the Board

- Saloni Thanki – Strategy, Impact and Relationships Board Advisor
- Karan Panesar – Youth and Finance Advisor

Staff

- Chief Executive Samantha Johnson
- Families & Community Lead Emma Orpin
- Income & Trust Coordinator Kate Smith
- Impact & Network Coordinator Vashti MacDonald-Clink
- Family & Volunteer Coordinator Marie Taylor
- Fundraising Lead Rebecca Holt
- Communications Co-Ordinator Yasmin Badesha – started 25/03/24
- Operations & Development Lead Cecilia Yardley
- Youth Worker Andrew Edherue

Leavers

- Lead Youth Worker Tania Weekes – left 10/5/24
- Communications Administrator Ethan Sheward - left 31/01/24

Independent Accountant

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

Bank

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

Letter from the Chief Executive

ECHO began 2024 with ambitious goals: to strengthen existing relationships, expand our front-facing services, and grow our income, so we could better serve the larger numbers of families affected by congenital and acquired heart conditions (CHD) turning to us with the merger of the Royal Brompton Hospital into the Guy's and St Thomas' NHS Foundation Trust. Like many charities, we were dealing with ongoing uncertainty—particularly around donor confidence, future funding, and rising costs.

Despite these challenges, our Board and staff remained focused on our mission to support children, and their families, treated for heart conditions by the Evelina London and other hospitals in the Guy's and St Thomas' hospital networks. We expanded into a wider geographical area and pushed forward with planned activities, embracing new opportunities and working with a wide range of partners to overcome the barriers faced by families living with CHD.

Some of the most iconic images from ECHO's photo library for 2024 come from our 40th anniversary celebrations at the Family Adventure Day at Stubbers outdoor centre. Between them, they capture many features of our work during the year.

The first images feature young people with heart conditions climbing a sheer tower that leads to a 'leap of faith'. This would be nerve-testing enough; one of the teenagers was registered blind, and the other (featured on p.14) has a leg brace.



In focusing on these individual acts of courage, it is easy to miss all the support and risk management that went into giving them the chance to push themselves and feel the thrill of succeeding.

Wearing safety harnesses with the ECHO community on the ground, anchoring the ropes that bring climbers safely down to earth after their leap of faith. Professional instructors on hand, the whole experience researched, risk assessed, covered financially and administered comprehensively by ECHO, so that these young people, their family, and the surrounding ECHO community can fully enjoy this moment of pure elation.

During Covid, ECHO's future was precarious. We stood on a tiny platform – with our staff team cut back by furlough and our volunteer base decimated. We had to make several leaps of faith to grab onto funding lifelines and rapidly embrace new ways of working. Growing in adaptability and resilience has prepared us for the challenges of these times.



A group shot of our staff and volunteer team at Stubbers shows how we've rebuilt capacity.

We are not back to pre-Covid volunteer numbers yet, but during 2024, we strengthened several elements of ECHO's internal infrastructure to be more robust and effective moving forward. Working closely with professional services partners in the NHS and third sector bodies, we began to enrich and extend our volunteer induction, training and support package.

We continued to invite clinicians from Guy's and St Thomas' NHS Foundation Trust to volunteer at a range of events, not just for their cardiac expertise, but also to create a mutually rewarding opportunity to meet with ECHO's young members outside the clinical setting.

After a thorough review of sector tools, we began our digital transformation towards more efficient, automated systems by investing in a new Beacon database. Alongside this, we introduced a new impact measurement framework, to steer how we gather data from families and other key stakeholders. We expect this to drive improvement by revealing new insights into our community's needs and what works best in meeting them.

ECHO's impact report from Stubbers -- the first underpinned by our new impact measurement framework – With ECHO Teens on its cover, sharing the pride of personal achievement and having worked well as a team. The attention to inclusivity and focus on physical, mental and emotional wellbeing that ran through that day is at the heart of all we do.



All those young people – and their parents, carers, siblings, and wider family – follow their own individual pathways of challenge, often navigating intense pressure, sadness, and difficulty. I walked a similar road myself, experiencing urgent cardiac care and surgery away from home, gaining firsthand insight into life after cardiac surgery and treatment. By early 2024, I was celebrating 10 years of working at ECHO while on a phased return, reflecting both the resilience required in recovery and the understanding it brings. In response to these challenges, ECHO connects people through shared information and personal stories, building a community where those affected are stronger together and inspire one another.

Thank You: Supporting families through difficult and emotional times is not just a job—it's a calling. The ECHO team brings deep care, dedication, and skill to everything they do. We thank them for their hard work and resilience this year, especially as we've juggled day-to-day responsibilities with major behind-the-scenes change. And to every supporter, fundraiser, partner, and donor—thank you. From children and young people, to schools, companies, and individuals—your generosity and heart make our work possible.

Having looked back at all ECHO undertook and achieved in 2024, we can look forward to the next 40 years embracing the Spirit of Adventure!

[Samantha Johnson CEO](#)



About ECHO

Established as a charity in 1983, to be independent from but work closely with the Evelina London and GSTT to support the parents of children with congenital (CHD) or acquired heart disease, ECHO still accomplishes this mission but has broadened its remit. We now offer support to the whole family of any child with a heart condition under the care of the Guy's and St Thomas' CHD network which comprises 47 hospitals including Evelina London, Royal Brompton and Harefield Hospitals and local hospitals across London, East and South East England that hold children's heart care outreach clinics from the specialist centres.

ECHO is a membership organisation. Parents/carers can self-refer and join ECHO at www.echo-uk.org/get-support/join/. Professionals who identify that a young patient, a sibling, parent, or the wider family needs support can make a referral to ECHO.

"ECHO has been a lifeline for me"

Congenital heart disease – abnormal development of the heart before birth – affects around one per cent of the population, and every year between 500 and 1000 children nationally acquire a heart condition. Thanks to dedicated medical care and advances in treatment and surgical techniques, more than 80 per cent of babies born with heart defects now survive into adulthood. ECHO works with and on behalf of families from diagnosis – often made at the antenatal anomaly scan – throughout all stages of the heart journey, from birth, through surgery and all forms of treatment, until the young person with a heart condition is 25 years old. If a member family is bereaved by losing the child with a heart condition, ECHO continues to provide support.

"We learn so much from our own community... parents signposting interesting things... making connections is one of the most important things. We have been at this a while, now want to pay it forward, help others who may be starting their journey... can talk, advise, tell them they will come out the other side."

ECHO emphasises inclusivity in its services, aiming to reach members from as wide a range of cultural and social backgrounds as possible. Our services are not means-tested and are fully funded to maximise participation across ECHO's membership.

The wraparound care that ECHO provides is not available through the NHS. It ripples out beyond hospitals, connecting members into a community who support each other through the challenges of CHD, which impacts all areas of life. We focus on the whole person so that children and young people are not defined by their heart condition and their families are not overwhelmed by it. Our vision is to enable every member to live life to the full through having their social, emotional, financial and medical needs met.

Highlights of 2024

The day-to-day work of ECHO consists of providing our core services, one caring conversation, a responsive email, an engaging social media post, and an efficient database update. But there are always milestone days and occasions that highlight the style of our work – supportive, open, inclusive, positive, and fun! Here is a selection of those moments during the year:



King's Engaged Researcher Awards

January

ECHO were finalists in the *King's Engaged Researcher Awards* for collaboration on the 'Heartificial Intelligence' installation at the Science Gallery London, co-created by ten members of ECHO Teens with artists, TripleDotMakers, and researchers from the Wellcome/ESPRC Centre for Medical Engineering at King's College London.

February

Members, staff, schools, and NHS colleagues joined in ECHO's annual 'Wear Red' for Heart Month campaign. We shared insights with health professionals about the experience of families living with CHD at the Evelina Neonatal Intensive Care Unit (NICU) **staff training day** and the **launch of Guy's and St Thomas' NHS Foundation Trust's Lifelong CHD Network**. Two members of ECHO Teens spoke from the panel at the **London School of Paediatrics' Conference** on 'Challenging Perspectives in Paediatric Care'.



Hadrian Academy Wear Red

March

We put on bunny ears and cheered on riders at the annual **Bunny Hop** organised by BMX Life which raised £3445.48 including Gift Aid. To brighten the stays of children and young people in the Evelina over the holiday, we delivered a range of **Easter craft packs for the play specialist to use** with them. We also provided **youth work support** to the Little Hearts Matter members' conference, organised by the national charity for **single ventricle heart conditions** to which many ECHO members also belong.



ECHO's London Landmarks runners

April

We **spoke at the launch of the NIHR HealthTech Research Centre** in Cardiovascular and Respiratory Medicine and participated actively at the **National Child Health and Wellbeing Council** meeting. An 11-strong ECHO Team, including one of our Trustees, conquered the **London Landmarks Half Marathon**.

"At our 12-week scan, we were told that there was an abnormality with our baby's heart. We received lots of support from ECHO, and their FB group was invaluable in making us realise that we're not alone."

ECHO parent and London Landmarks runner

May

Regular fixtures in ECHO's calendar for May are the ECHO Teens' expedition **'Up and Over'** the O2 in London, followed by a slap-up meal, and the appearance of Eddie ECHO Bear as the mascot at the annual **football match in aid of ECHO** arranged by one of our member families.



June

The Grand Finale of ECHO's

40th Anniversary year was the **Family Adventure Day** at Stubbers that brought together over 40 families, with a total of 89 children aged from under one to 18 years old. They enjoyed a packed programme of physical and wellbeing activities and an evening BBQ.

ECHO Teens took part in an **online drama workshop** themed around the Lion King musical. We met the public at the Guy's and St Thomas' **Armed Forces Day** and led a physical activity session at the Sussex Hospitals **Transition Day in Brighton**.



July

Eighteen **ECHO Teens** came together in London for **lunch out and a theatre trip** to see the Lion King musical. ECHO team members **visited the cardiology outreach clinic** at the Princess Royal University Hospital in Bromley to explore how best to support families across the Guy's and St Thomas' heart care network, and we gave a **presentation to nurses** from across the southeast region about the ECHO community and what we offer the children and families they care for.



August

Many medals were the order of the day for inpatient young people, their siblings and families when, in partnership with the Evelina's play workers, we encouraged them to swap the wards for ECHO's **active fun afternoon**, including football and races in the park, and bocce, darts, and ping pong indoors.

September

For **World Heart Day**, ECHO Teens joined an online drawing workshop to create their own **'Heart Hero'** character. Brianna, the ECHO Teens member who danced live on TV for Children in Need 2023 was invited back to **The One Show on BBC1** and embodied the message that heart conditions do not have to hold young people back.

October

Members old and young joined in Halloween fun with ECHO, including a **spooktacular art session** in the Evelina. Our Black History Month Tea Trolley at the Evelina was warmly received by staff and families.



Taking a moment with ECHO in the hospital is a real help, I made something, and they didn't need me to think about it much – they were there to help and listen

November

ECHO's *Diversity Ducklings* were a hit again at the **British Congenital Cardiology Association's annual conference** where we gathered ideas for resource cards to help young people manage their transition to adult services. Our youth worker exchanged insights with peers at the **Health-based Youth Workers' annual conference**. We donned our **posh frocks** to fundraise at the 1000-guest **Statom Charity Ball**, the construction industry's highlight of the social calendar. **ECHO Teens enjoyed Festive Fun**, with the 11- to 17-year-olds who met in person going bowling and dining out, while those who got together online enjoyed an Olympic-themed games evening. The 18- to 25-year-olds enjoyed hot chocolate and a meal together surrounded by the magical lights and festive buzz of the city.



December

BMX Life Santa Cruise 10 saw more than 1000 BMXers ride through London dressed as Santas, elves, Grinches, reindeers, and Christmas trees to raise £21,570.56 plus Gift Aid for ECHO. At their stop-off at the Evelina, they and the patients were serenaded by the **Stratford East Singers**. **Santa's Little Helpers** (aka **corporate volunteers** from NatWest and MACE) wrapped hundreds of donated books, toys, and treats that were delivered in the Evelina by **ECHO's Christmas Elves**, spreading joy through the cardiac ward, intensive care, and high dependency units.



ECHO's direct services to members in 2024

- **Website** (www.echo-uk.org), **publications, and video resources** on YouTube to provide guidance and reassurance and support decision-making.
- **Private Facebook Group** moderated by ECHO with 1,600 members in which parents provided peer-to-peer support.
- **Online group social, learning, and support events** including sessions run in partnership with healthcare professionals.
- **In-person ECHO Community events** so that children, young people and families could connect for fun, friendship, inspiration and encouragement.
- **Buddying and mentoring** by experienced members of the heart community who shared knowledge and encourage others facing challenges.
- **Conversations and support emails** to enable parents/carers to think through care choices and be referred, where necessary, to specialist agencies.
- **Evelina London family and youth work support**
 - Visits several times a week by staff and volunteers to the children's and young adults' heart care in-patient and out-patient treatment areas, with a weekly Tea Trolley for families and staff on the paediatric cardiac ward.
 - Pre-consultation listening to prepare for meetings with clinicians, with support and note-taking offered during the clinic.
 - Drop-in visits by families to ECHO's office over the road from the Evelina London.

"We were introduced to ECHO during my pregnancy when we found out about my son's issues at the foetal scan. The Facebook page has been a huge help, with so much support and advice given." ECHO Parent

We provided specific services to the following groups:

- **Parents-to-be:** In partnership with the midwives' team at Evelina London, ECHO parent volunteers delivered talks about how to prepare for giving birth to a child with a heart condition, the treatment and aftercare, answering questions from parents-to-be at nine special cardiac antenatal classes online, approximately one every six weeks.

- **Young people aged 11-25:** ECHO ran regular activities online – including art and drama workshops -- and in-person – including a trip to the Lion King musical and a climb ‘Up-and-Over’ the O2 in London. These events gave young people with a heart condition and their siblings secure opportunities to build friendships, have fun together, learn new skills, talk about their fears and their hopes and gain confidence in managing life with CHD.
- **Bereaved families:** Always welcome to ECHO’s community events, we also provided dedicated time to our bereaved families with a special Christmas Lights Tea Bus tour – third time lucky after the 2024 train strikes caused two previous trips to be cancelled.



Christmas Lights Tea Bus

Support via local hospitals

To improve the experience for young heart patients attending clinics close to home, ECHO supplied resources to hospitals that hold outreach clinics from the Evelina and Royal Brompton and Harefield hospitals including the Eddie & Friends activity magazine for younger children, and small items of equipment not funded by the NHS -- such as sound spas and gel warmers -- to relieve the stress of tests.



Black History Month Tea Trolley on cardiac ward

Service developments in 2024 by target group

Parents/carers of children diagnosed with a heart condition

ECHO is a trusted partner of the Guy’s and St Thomas’ NHS Foundation Trust, the biggest centre in England, Wales, and Ireland treating CHD in children and adults. Our staff hold honorary NHS contracts and, in 2024, we continued to work closely with the various specialist teams that treat and support children with a heart condition at the Evelina. We provided ‘in-reach’ support several times a week into ECHO’s customary settings in the Evelina -- outpatients department, cardiac ward, and Paediatric Cardiac Critical Care -- as well as extending the footprint of our work to the Paediatric Intensive Care Unit and the Neonatal Intensive Care Unit.



During these visits, we gave out *ECHO Cares* welcome packs to provide immediate practical and emotional support to each family and invite them to join the ECHO community. To provide distraction and relieve anxiety we supplied arts and crafts packs for families to use with the play team, and to keep Mother’s and Father’s Day special during a stay in the Evelina, we gave out gift bags to parents staying at their child’s bedside.

“ECHO have been part of our lives for 11 years. They were so supportive and amazing to my family. Not just to our heart baby, or me, but to our whole family. I volunteer as a way of saying a massive thank you to ECHO!”

Parent and volunteer

By gently encouraging parents to take short breaks for their own wellbeing, including coming out to the weekly tea trolley on the cardiac ward, the ECHO team were able to introduce families to one another. In line with our commitment to inclusion and diversity, we had two 'firsts' in our offer at the Evelina: a Black History Month-themed tea trolley in October, with goodies sourced solely from Black-owned businesses, and the gift of halal sweets, fruit and Eid-themed items to Muslim families to mark the end of Ramadan.

As parents gain knowledge by living through the different phases of their child's treatment, they start to become 'experts by experience'. Facilitated by ECHO's introductions and opportunities to meet, in real life and virtually, parents were able to support one another on the ward, through ECHO's private Facebook group, and through a series of eight online sessions we launched in partnership with the Evelina psychology paediatric cardiology team.

We increased **two-way engagement** with our community by making greater use of videos and polls on social media. To bring ECHO's work to life and show the emotional and practical support ECHO provides at every stage of a family's journey, we created new **visual and voice case studies**. These share real-life family journeys that highlight ECHO's role and will make a difference to families who are newly diagnosed and those who want a better understanding of the range of experiences across the CHD community.

Younger children

We continued to provide Eddie ECHO bears to younger children, as a comfort during hospital stays and a friend outside the hospital. Taller members of the ECHO team dressed in the Eddie mascot suit to bring a smile to children on

the ward and at ECHO events. Our *Eddie and Friends* magazine, complete with stickers of all the characters, and our Eddie-themed colouring sets and ever-changing range of child-friendly arts and craft activities proved extremely popular throughout the year.

ECHO Teens

Under the banner of *ECHO Teens*, ECHO continued to provide a mix of online and in-person activities for 11- to 17-year-olds and 18- to 25-year olds affected by CHD -- both heart patients and their siblings -- to meet others facing similar challenges and form friendships.



“Joining ECHO Teens is honestly one of the best things that happened to me. I met great youth workers and Sam who welcomed me into the ECHO family and an amazing group of young people, who inspired me with their stories.”

Being bullied by their peers at school and not being allowed to go on trips or join in physical activities are widely reported by young people with a heart condition, so, to belong to a group in which they do not stand out as different and are accepted, valued and encouraged to join in is both novel and very precious to many ECHO Teens.

The youth group's programme in 2024 was based on suggestions from the young people themselves and included trips to cultural and leisure activities, meals out, discussion

groups, arts-based workshops, games and fun physical activities. Led by ECHO's youth worker and facilitated by professionals with expertise in youth work, art, drama, community engagement, and other relevant specialisms, the content of sessions was always designed to

help the young people grow in confidence and social skills while enjoying themselves.

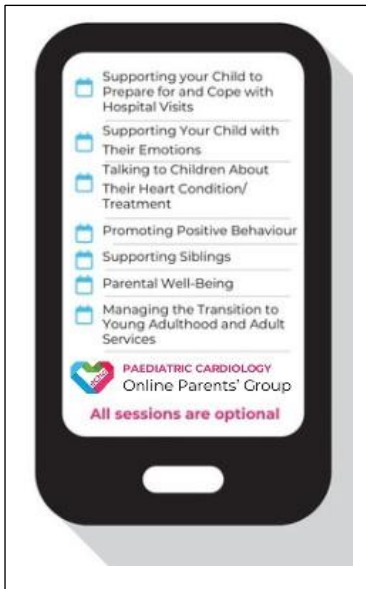
During the year two ECHO Teens members did work experience placements in the ECHO office, giving invaluable input to a set of resource cards being developed to help young people with CHD manage their wellbeing, particularly as they face the challenges of transitioning to adult services at the same time as intense pressure at school.

Collaboration with professionals

We often act as a conduit for two-way information exchange between our members and the NHS or cardiac researchers. When the **cyber-attack on Synnovis** led to disruption over several weeks in hospitals across the Guy's and St Thomas' Trust, we provided ECHO members with reliable status updates, to allay fears and help them plan their child's care.



21st London CHD Course



With a view to making services and technological solutions for CHD more responsive and fit-for-purpose, we promoted

consultation activities by the **Guy's and St Thomas' Lifelong CHD Network** and the **HealthTech Research Centre**. We also publicised the **Paediatric Cardiology Psychology** team's 'Take a Breath' group for families of newly-diagnosed children and jointly launched the new eight session **online psychological support programme** for parents.

To build awareness among professionals and encourage referrals, ECHO team members supported NHS colleagues at several events, including a **Transition Day in Brighton**, where our youth worker ran a physical

activity session as part of a programme to enable Sussex-based young people undertake their transfer to adult services. He followed this up with an online presentation to NHS professionals in the region about 'teen-friendly' ways ECHO engages with young people to prepare them for this important milestone in their care. We delivered our summer afternoon of active fun for inpatients and their siblings in **partnership with the Evelina paediatric specialist team**.



We continue to supply small items of equipment not funded by the NHS, such as sound spas and positioning aids for babies, for health service colleagues to use to make the experience of clinics and treatment more comfortable and less stressful for young CHD patients.

We presented on ECHO's support at a **Southeast region CHD nurses training day** and met with delegates on our stands at the **21st London Congenital Heart Disease Course** and the **British Congenital Cardiology Association's annual conference**. We continued our active participation in the **King's Community and Health Research Board** to strengthen ECHO's links to community groups that could support our members in Lambeth and Southwark, and the King's College/NHS clinical and biomedical research community with whom we regularly collaborate.

Over recent years, to pilot ECHO's engagement with Level 3 cardiology units, we have built a close relationship with the local clinicians who deliver cardiology outreach clinics at the Princess Royal University Hospital in Bromley. Growing out of our collaboration during 2024 is a **new animation and supporting literature for young children**, to reduce their anxiety

around clinic visits. Planned to launch in 2025, these resources should save the NHS money in clinic time currently lost because of the distress of young patients having tests.

Building our team

Volunteers

In 2024, we recruited seven new ward volunteers, three administration and fundraising volunteers, 12 event volunteers and 33 corporate fundraisers. We worked closely with the Guy's and St Thomas' volunteering service team to enhance our volunteer recruitment process so that it dovetails seamlessly with the Trust's. Volunteering with families affected by CHD can be demanding emotionally, so we took time to address all the dimensions of each different role to properly prepare all those who generously give their time to ECHO.

Strengthening our infrastructure

Building Stronger Foundations: One of the most significant achievements this year was the introduction of a new organisational database. After a thorough review of sector tools and systems, we chose **Beacon**, a dedicated charity CRM with equally strong functionality in fundraising and service delivery, to replace ECHO's outdated processes. This marks the start of our digital transformation—laying the groundwork for more efficient, automated systems that will increase our capacity and improve how we support families. This shift has not come without effort. Staff and volunteers put in substantial work alongside their existing roles to make this possible, and we are grateful for their energy and commitment.

New volunteers all set for a ward visit



Changes to How We Report Our Impact

As part of a wider review of our work — what we do, why, and who for – we drew on the insights of the ECHO Board, staff, volunteers, members, and external experts, to develop and introduce a new impact measurement framework that will change how we collect and use feedback from families. Our goal has been to make impact measurement part of our everyday culture, ensuring everything we do reflects what families truly need.

Previously, we faced barriers including limited time, tools, and funding. Now, our team has a clearer approach to measuring impact and knowing when to do it. Moving forward, this will help us better communicate our impact to funders and partners and improve the way we support families. Supporters may notice some updates at events and in our forms as part of our commitment to working in a more focused, meaningful way.

Fundraising and Corporate Support

Thank you so much to everyone who ran, baked, biked, sky-dived, quizzed, danced, gifted, walked, trekked, BBQed, lit up their house, dressed up, dressed down, kicked, passed or batted a ball – or did anything else to raise money for ECHO to help families affected by a child's heart condition.



Financial Review

Reserves policy 2024 – I have kept the essence of the 2023 section but edited it down, leaving the substantive information Jane to check if any changes

ECHO recognise the amount of reserves we need may vary year on year, COVID-19 brought changes to all charities and the impact of this, and the current cost of living crisis are still being felt. It has meant ECHO are looking closely at making sure we can secure our future and support more families. With this, the Trustees have agreed the following reserves policy.

If we are to continue to innovate and provide & current services to those we support, additional funding will be necessary to enable these services to be provided.

Planning for unforeseen emergencies and day-to-day operational costs: ECHO continues to support an increasing number of people, and we must hold an amount in reserves as a contingency against unforeseen costs for the future.

Uncertainty over future income or ability to raise funds linked to cost-of-living crisis: As we rebuild our in-person services post Covid-19, ensuring reserves are robust provides confidence.

Specific costs recognised: ECHO office plans to be demolished in the foreseeable future meaning we will need to move our operations; also the changes to London Landscape of children's heart surgery through NHS England could double the number of families needing our support.

With this all-in mind the Trustees now want to maintain free reserves in unrestricted funds at a level which equates to approximately 4-9 months of unrestricted charitable expenditure

A new strategy is being put in place, one of expansion of service provision which will increase the range, breadth, and frequency of services we provide to those we support, our investments in the services we provide will benefit more families from across the children's heart community.

ECHO wants to ensure the services and charity can deliver the work to all who need it as well as in case of another funding crisis. We have been informed that ECHO's current office will be demolished sometime between 2026/2027. The board has designated £120,000 of our reserves to ensure we will be able to rent a suitable space at full market cost (we currently pay reduced rent), provide a safe place to work for staff and volunteers and the families who need us, as well as staying local to the children's hospital in central London. This figure represents 2-3 years of costs attributed to moving and renting new premises.

Community and events

Fundraising remains the lifeblood of ECHO, enabling us to deliver vital support, services, and events that bring our community together. These gatherings provide shared experiences, learning, and encouragement, reinforcing the strength found in connection. We extend a special thank you to BMX Life for their ongoing support and partnership, which has helped make these events both inspiring and memorable for everyone involved.

Trusts and Foundations We are deeply grateful to the trusts and foundations that supported our work throughout 2024, contributing a total of **£128,841**.

Special thanks to:

- City Bridge Trust - Whitehead Monckton Charitable Foundation
- Fowler Smith and Jones Trust
- Co-op Local Community Fund, the Toy Trust
- The Glenswood Charitable Trust
- Edith Florence Spencer Memorial Trust and Sainsbury's

Risk management

The trustee's meet approximately every 12 weeks are responsible for the general control and management of the charity. Each Trustee holds a portfolio area and together, they keep ECHO's financial resilience and risk profile in view and ensure that ECHO's policies to manage risks are developed and updated. ECHO has a plan to protect against a downturn in the level of its income. Staffing risk is managed through robust HR practices, as advised by an external HR company, and volunteer risk is managed through a volunteer process co-developed with NHS

Professional Services. As ECHO works with children, young people and vulnerable adults, all staff and volunteers are subject to Disclosure and Barring Service (DBS) checks. All staff work to contracts with clearly described conditions and are expected to follow the procedures outlined in comprehensive employment and staff handbooks updated each year and discussed at regular team meetings. The charity prioritises the safety of our members and beneficiaries, as well as the wellbeing of staff and volunteers.

Safeguarding

Safeguarding is paramount to us, all staff undergo training provided by NSPCC and/or Guy's and St Thomas' NHS Foundation Trust, and we ensure that all volunteers have access to training, policies, and support they need working with children, young people, and vulnerable adults. We have a safeguarding policy and a statement that is assessable via the ECHO website. All trustees, volunteers, and staff attend safeguarding training relevant to their role.

Key Risks and Mitigations

The demand for ECHO's support is growing across all areas of our work. We are seeing more mothers and carers attend ECHO Antenatal Classes, young people taking part in *ECHO Teens*, and families who want support. Some examples of risks identified in 2024 include:

- The need to support almost double the number of members with changes to the London Landscape of children's heart services impacting the number of families joining ECHO

We regularly review services to meet the needs of members and keep abreast of future and current changes, identifying how other stakeholders are working through frequent information exchange meetings and presence on decision-making bodies.

- Demand from the network with the potential for an inequitable offer across our region

To ensure our offer is equitable, regardless of where it is delivered, we liaise closely with the Lifelong CHD Network Leads and place greater emphasis on visits to units and involvement in network events for rapid 'temperature taking' of needs on the ground.

- Technology introducing a new database in 2024 and across 2025 will bring challenges but enable us to increase ECHO's efficiency and improve relationship management across the supporter base. This should help us to maximise support opportunities, including fundraising and volunteering, to increase the charity's resilience.
- Staff burnout

As the needs for our services grow, ECHO is spending time to ensure we are resilient and here for a long time in the future. We hold regular supervision and wellbeing meetings with the team with development, work-life balance, and emotional support conversations at their core.

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, appointment, and development of trustee directors

The directors of the company are also charity trustees for the purposes of charity law. The minimum number of trustee directors is 5, and there is no maximum. Questions arising at a meeting are decided by majority votes.

ECHO has a skills matrix and reviews its governance arrangements every year to ensure the Board has a strong mix of competencies and experience to develop and deliver strategy

effectively for members. As we have emphasised inclusion more strongly operationally, we recognised the need to diversify the Board and, therefore, created two new Special Advisor roles for a year. During this time, the advisors have been able to gain skills and insights into charity sector governance, that would enable them to apply for substantive roles on ECHO's Board at the end of the advisorship. Both roles were filled by colleagues with invaluable professional expertise who are also experts by experience in relation to CHD.

Saloni Thanki, whose background is in technology, security, and risk transformation in financial services, has steered ECHO's work on impact measurement. Saloni's family has received CHD treatment and support from the Royal Brompton Hospital, strengthening ECHO's ability to recognise and respond to needs of families brought into the merged Guy's and St Thomas' CHD Network from there. She has also brought a strong commitment to embedding best practice in mentoring, diversity, equity and inclusion into ECHO's practices.

Karan Panesar has had been closely affiliated with ECHO since 2011 when he was first treated at the Evelina. Heavily involved in ECHO Teens as a volunteer, Karan draws upon his personal experience with CHD to mentor young people on how to live well with a heart condition, especially during the transitional period between paediatric and adult care. Having recently qualified as a Chartered Accountant, Karan joined ECHO as a Board Advisor to help steer the charity's finances whilst maintaining his role as a youth ambassador.

Plans for the future - What's next?

This year has been about laying the groundwork—digitally, operationally, and culturally. We're committed to measuring our impact more clearly, improving our services, and responding directly to what families tell us they need.

Looking ahead for 2025 we plan to:

- Secure ECHO's position within the landscape of care to families affected by CHD, taking account of changes in our operating environment, including the increased patient flows into the Evelina from the Royal Brompton hospital, the introduction of children's cancer services at the Evelina, and the higher costs of staffing because of changes in employer costs introduced by the government during 2024.
- Diversify our offer of events and activities to the ECHO community, introducing new elements from the Evelina as a 'hub' and continuing to provide fully-funded opportunities for families to meet one another in person, but also online opportunities for those for whom travelling may be difficult.
- Continue to give families high quality information that builds their confidence to manage life with CHD through an updated website and new cardiac support resources including an animation and leaflet to help younger children prepare for a clinic visit, videos covering personal accounts of living with CHD, and a film made by and for young people to support others going through transition to local services.
- Complete the implementation of our new volunteer recruitment, management, and development processes to extend our volunteer base to deliver across a wide variety of roles
- Introduce new film and animation resources and build virtual and in-person opportunities for the wider network to access support.

As I look back over 2024, I am filled with pride and gratitude for all that we have achieved together as the ECHO family.

This year was especially significant as we celebrated our 40th anniversary. The highlight for me was the Family Adventure Day at Stubbers, where I watched young people with heart conditions – some climbing with leg braces, some even without sight – summon incredible courage to take their "leap of faith." What struck me most was not just their bravery, but the

way their families, our staff, volunteers, and clinicians stood together to make those moments possible. It reminded me that ECHO is about so much more than events and activities – it's about creating a safe, supportive community where families can thrive, even in the toughest of times.

Throughout the year, we've continued to grow stronger. We invested in new systems, like our Beacon database and a fresh way of measuring our impact, so that we can listen more carefully to families and respond to their needs. These changes may be behind the scenes, but they mean we can give better support to every parent, young person, and child who turns to us.

I've been especially inspired by ECHO Teens. Seeing them come together – whether climbing the O2, enjoying a theatre trip, or simply sharing their experiences – shows how vital it is for young people to have a place where they feel understood, accepted, and encouraged. Their laughter, confidence, and friendships are a wonderful reminder of why we do this work.

We couldn't have done any of this without the generosity and commitment of our supporters. From marathons and bike rides, to BMX Life's unforgettable Santa Cruise, to the many families and friends who baked, quizzed, donated, or gave their time – thank you. You have kept ECHO strong, and every pound raised and every hour volunteered has made a real difference to families facing the challenges of childhood heart disease.

Finally, I want to say a heartfelt thank you to our incredible staff team, led by Samantha Johnson. Their compassion, energy, and resilience have shone through a year that has demanded both day-to-day care and big changes for our future. To my fellow trustees and our new advisors, thank you for your wisdom and commitment – it is a privilege to serve alongside you.

As we step into 2025, we do so knowing the demand for ECHO's support is growing. But we also know that with the spirit of adventure that has defined our first 40 years, and with the strength of this amazing community, we are ready for whatever comes next.

From the bottom of my heart, thank you for being part of ECHO's journey. Together, we ensure that no family faces this road alone.

With warmest wishes,

Stephen Wood

Chair of the Board of Trustees

Declaration

The trustee directors declare that they have approved the trustee directors' report above. Signed on behalf of the charity's trustee directors: **Steve Wood, Chair during 2024**







www.echo-uk.org @echoukcharity

EVELINA CHILDREN'S HEART ORGANISATION
(A company limited by guarantee)

Registered Charity number 1146494

Company Number 07867592

ACCOUNTS FOR THE PERIOD FROM 1 JANUARY 2024 TO 31 DECEMBER 2024

Evelina Children's Heart Organisation Limited
Accounts for the period from 1 January 2024 to 31 December 2024

Charity Name Evelina Children's Heart Organisation Limited
Working Name ECHO
Charity Number 1146494
Company Number 07867592
Registered Office Canterbury House, 1 Royal Street, London. SE1 7LL

Board of Trustee Directors

Patricia Jane Ward
Joanna Eyeson
Alex Bicknell
Stephen Wood Chair
Marc Harry
Lynne Powrie Resigned 26 April 2024
James Pincus Appointed 8 May 2024

Independent Accountant Danestone Business Services Ltd
52 Crown Drive, Inverness. IV2 3QG

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

Evelina Children's Heart Organisation Limited
Statement of Financial Activities
For the period from 1 January 2024 to 31 December 2024

	Unrestricted Funds Period Ended 31 December 2024 £	Restricted Funds Period Ended 31 December 2024 £	TOTAL FUNDS Period Ended 31 December 2024 £	TOTAL FUNDS Period Ended 31 December 2023 £
Incoming Resources				
	(Note 3)			
Donations	215,321	111,773	327,094	320,782
Investment Income	4,649		4,649	3,380
Gift Aid	621		621	912
Total incoming resources	<u>220,591</u>	<u>111,773</u>	<u>332,364</u>	<u>325,074</u>
Costs of Providing Charitable Activities				
	(Note 4)			
Cost of fundraising	107,854		107,854	71,193
Charitable Activities	286,367	68,064	354,431	283,720
Governance	784		784	776
Total Resources expended	<u>395,005</u>	<u>68,064</u>	<u>463,069</u>	<u>355,689</u>
Net movement in funds	<u>(174,414)</u>	<u>43,709</u>	<u>(130,705)</u>	<u>(30,615)</u>
Reconciliation of funds				
Total Funds brought forward	<u>207,318</u>	<u>77,248</u>	<u>284,566</u>	<u>315,181</u>
Total Funds carried forward	<u>32,904</u>	<u>120,957</u>	<u>153,861</u>	<u>284,566</u>

Evelina Children's Heart Organisation Limited
Balance Sheet as at 31 December 2024

		31 December 2024 £	31 December 2023 £
Fixed Assets	(Note 5)	5,007	8,405
Current Assets			
Debtors/Prepayments	(Note 6)	2,011	5,008
Cash at bank and in hand		156,003	274,657
Total Current assets		<u>163,021</u>	<u>288,070</u>
Creditors falling due within one year	(Note 7)	(9,160)	(3,504)
Net Assets		<u>153,861</u>	<u>284,566</u>
Funds of the Charity			
Unrestricted Funds		32,904	87,318
Unrestricted Designated funds	(Note 8)	0	120,000
Restricted Funds	(Note 9)	120,957	77,248
Total Funds		<u>153,861</u>	<u>284,566</u>

For the year ending 31 December 2024 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

* The members have not required the company to obtain an audit of its accounts for the year in question in accordance with section 476

* The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts.

These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime

STEPHEN WOOD

Chair

S Wood

Date:

15th September 2025

Evelina Children's Heart Organisation Limited
Notes to the Accounts

Note 1: Accounting Policies

The principal accounting policies are summarised below. The accounting policies have been applied consistently throughout the period.

Basis of Accounting

The financial statements have been prepared on the basis of the historic cost convention and in accordance with the Companies Act 2006 and the Statement of Recommended Practice - Accounting and Reporting by Charities (SORP 2005) issued in March 2005.

Fund Accounting

Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity. Restricted funds are subjected to restrictions on their expenditure imposed by the donor.

Incoming resources

All incoming resources are recognised once the charity has entitlement to the resources, it is certain that the resources will be received and the monetary value of incoming resources can be measured with sufficient reliability. Grants and donations are included in the SoFA when the charity has unconditional entitlement to the resources and incoming resources from tax reclaims are included at the same time as the gift to which they relate. Investment income is included when receivable.

Resources expended

Expenditure is recognised on an accrual basis as a liability is incurred. Costs of generating funds are those costs incurred in attracting voluntary income.

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its members. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature to support them.

Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include independent examination fees and costs linked to the strategic management of the charity.

All costs are allocated between the expenditure categories of the SoFA on a basis designed to reflect the use of the resource. Costs relating to a particular activity are directly allocated.

Fixed assets

Tangible fixed assets are stated at cost less depreciation. Depreciation is provided at rates calculated to write off the cost useful life as follows:-

Computer equipment - 33.33% straight line basis
Fixtures & Fittings - 33.33% straight line basis

Note 2: Trustees Remuneration

No remuneration was paid to the trustees in the 12 month period ended 31 December 2024

Note 3: Analysis of incoming resources

Voluntary income:

Unrestricted donations

Restricted donations

Investment income:

Bank Interest

Total

Total Funds
12 month period to
31 December 2024
£

215,942

111,773

4,649

332,364

Note 4: Analysis of
charitable activities

Back Office/Admin

Volunteers

Information

Member Support

Total

12 month period to
31 December 2024
£

95,844

1,687

18,155

238,745

354,431

Note 5: Fixed Assets

	<u>Fixed Assets</u>
	<u>£</u>
<u>Cost</u>	
At 1 Jan 2024	20,453
additions	3,120
At 31 Dec 2024	<u>23,573</u>
 <u>Depreciation</u>	
At 1 Jan 2024	12,048
Charge 2024	6,518
At 31 Dec 2024	<u>18,566</u>
 <u>Net Book Value</u>	
At 1 Jan 2024	8,405
At 31 Dec 2024	<u>5,007</u>

Note 6: Analysis of Debtors/Prepayments

	<u>£</u>
Prepayment : Tax	11
Prepaid expenses cards	2,000
	<u>2,011</u>

Note 7 : Analysis of Creditors

	<u>£</u>
Trade creditors	8,093
PAYE, NIC, Pension	1,067
	<u>9,160</u>

Note 8 : Unrestricted Designated Funds

	<u>£</u>
Provision for office space for 3 years as current office to be demolished and rebuilt.	<u>120,000</u>

Note 9 : Ringfenced Income

	<u>£</u>
Balance B/F	77,248
Ringfenced Donations	111,773
Expenditure	(68,064)
Balance C/F	<u>120,957</u>

Management Accounts for 2024

<u>Income</u>	<u>£</u>
Donations	£327,094.00
Interest	£4,649.00
Gift Aid	£621.00
TOTAL INCOME	<u>£332,364.00</u>
<u>Costs</u>	
General Admin	£38,361.00
Fundraising	£17,307.00
Promotional Items	£11,589.00
Staff Costs	£319,218.00
IT Costs	£22,794.00
Charitable Activities	£47,919.00
Volunteer Costs	£1,687.00
Legal & Governance	£4,194.00
TOTAL COSTS	<u>£463,069.00</u>
Excess Income/Costs	<u><u>-£130,705.00</u></u>



Section A

Independent Examiner's Report

Report to the trustees

Charity Name
EVELINA CHILDREN'S HEART ORGANISATION LIMITED

**On accounts for the year
ended**

31 DECEMBER

**Charity no
(if any)**

1145494

Set out on pages

1-7

(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31/12/2024.

**Responsibilities and
basis of report**

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

**Independent
examiner's statement**

The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of The Institute of Chartered Accountants in England and Wales.

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

** Please delete the words in the brackets if they do not apply.*

Signed:

Melza Linfield

Date:

8 SEPTEMBER 2025

Name:

MELZA HELEN LINFIELD FCA

**Relevant professional
qualification(s) or body**

ICAEW

(if any):

Address: DANESTONE BUSINESS SERVICES LIMITED
52 CROWN DRIVE
INVERNESS, IV2 3QG

Section B

Disclosure

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

EVELINA CHILDREN'S HEART ORGANISATION LIMITED

England & Wales - Charity number 1146494

Accounts



EVELINA CHILDREN'S HEART ORGANISATION LIMITED

(A Company Limited by Guarantee)

Registered Charity Number 1146494

Company Number 7867592

REPORT OF THE BOARD OF TRUSTEE DIRECTORS

FOR THE PERIOD 1 JANUARY 2023 TO 31 DECEMBER 2023

Evelina Children's Heart Organisation Limited
(A company limited by guarantee)

Report of the Board of Trustee Directors for the Period 1 January 2023 to 31 December 2023

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 Stephen Wood
Treasurer Alex Bicknell

Trustees

- Alex Bicknell
- Joanna Eyeson
- Stephen Wood
- Marc Harry
- Jane Ward
- Lynne Powrie

Staff

- **Chief Executive** Samantha Johnson
- **Families & Community Lead** Emma Orpin
- **Income & Trust Coordinator** Kate Smith
- **Impact & Network Coordinator** Vashti MacDonald-Clink
- **Lead Youth Worker** Tania Weekes
- **Communications Coordinator** Louise Creasy (employed 09.01.23)
- **Family & Volunteer Coordinator** Marie Taylor (employed 09.01.23)
- **Communications Administrator** Ethan Sheward (employed 07.08.23)
- **Fundraising Lead** Rebecca Holt (employed 07.08.23)
- **Operations & Development Lead** Cecilia Yardley (employed 14.08.23)
- **Youth Worker** Andrew Edherue (employed 29.08.23)

Leavers

- **Communications Coordinator** Louise Creasy (09.01.23 – 10.07.23)

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

Big birthdays are always a chance to take stock, and so it was for ECHO in our 40th anniversary year which began in June 2023.

We have stayed true to the charity's founding mission to **“provide information, friendship and support when parents or carers of a child with a heart condition treated at the Evelina London feel alone or need guidance”** and were delighted to honour Michael Joseph, the first paediatric cardiologist at the Evelina London, who set up the charity, by naming the family room at our office after him. We often host drop-in visits in that space from families visiting the Evelina, and now proudly display a wonderful cartoon portrait of Dr Joseph presented to ECHO in April by his daughter, Charlotte.

Though the essence of our family support has remained the same over the decades, the geographical focus has **expanded from Evelina London to all the 47 hospitals within the merged Guy’s and St Thomas’ Lifelong CHD Network which reaches from Norfolk to the South Coast.** We criss-crossed our ‘patch’ from Hemel Hempstead, to Sevenoaks, Chatham and Eastbourne, to capture on film stories that represent the diverse experiences of our member families, enacting the Trustees’ 2022 commitment to make ECHO’s services as representative and inclusive as possible.

As a practical response to the challenge of travelling long distances for treatment, one of the pieces of work I am proud of this year is Our Diverse Neighbourhood <https://echo-uk.org/neighbourhood>, a new mapping resource that connects families with shops and facilities around the Evelina London.

Many families, from a wide range of backgrounds **face experiences of separation from their local support networks in the unfamiliar surroundings of central London.** So regular visits to the wards from our Family Support and Youth Work teams provide a point of contact and continuity between families in the hospital and the wider heart community, who continue to be an amazing source of peer support to one another.

In November 2023, I ignored my own advice not to take your work on holiday with you: on leave in America, I had a heart attack and surgery from a previously undiagnosed inherited heart condition. This was, perhaps, the ultimate ‘taking stock’ experience from which I now have a deeper and truly personal understanding of the challenges ECHO members face. Throughout my recovery – which is going well – I have seen how resilient ECHO has been, partly due to the introduction in 2023 of a new senior Leadership Team which has strengthened the charity’s resilience and the ongoing commitment of our committed board of trustees.

Thank you to EVERYONE who has supported ECHO this year, through fundraising, volunteering, and getting involved in our community. Stick with us! We have lots to do, with many families needing our support. A very personal thank you to everyone who needed to step forward and act throughout my treatment, including the brilliant and fun staff team, our clever and committed board and all the amazing members, volunteers, partners and friends who reached out with kind messages – these moments won't be forgotten.

Finally, to confirm, as the charity moves into the second half of its anniversary celebrations, life begins at 40!



Warmest good wishes *Samantha*
Samantha Johnson, Chief Executive Officer

About ECHO

ECHO is a charity supporting families affected by children's heart conditions who have been treated by teams at the Evelina London, Royal Brompton and Harefield, and their network of local community hospitals. ECHO welcomes families into a community of shared experience and understanding and provides practical and emotional support at every stage of their heart journey.

Our services include:

- Specialist antenatal classes, reducing anxiety and worries parents may have about the birth and their child's health. We fund a midwife team to run 9 classes each year online under the specialist care of the Thames Tower Midwives.
- ECHO Teens group provides information, support, and guidance for teens in their transition from children's to adult cardiac services, as well as fun days out.
- Support for siblings, as siblings often have the feeling of loss of a "normal" family life, and the loss of their identity within the family.
- Wellness days/community days for family meetups, so families in similar situations can connect.

For our members, there is no alternative to ECHO. The help we provide is not available via the NHS or any of the hospitals or agencies we work with.

"ECHO have been the support circle that our friends and family couldn't give. On our following visits to the Evelina whilst the journey didn't get any less scary, ECHO helped us from the random questions in the middle of the night to the posts of hope and support and the lifelong friends we have made." ECHO parent

2023 marked the start of our 40th year celebrations!

2023 marked 40 years of ECHO, which was founded in 1983 by Dr Michael Joseph, the first Pediatric Cardiologist at Evelina London with parents of children with heart conditions. We have received ongoing support from our wonderful ECHO heart community made up of families, supporters, and medical staff. This year we celebrated four decades of providing for those with congenital, acquired, and inherited heart conditions and their families.



To mark ECHO at 40, we collaborated with several ECHO community members to share their stories by film. Filming at home and at Ronald McDonald House, we captured a range of experiences and represent family perspectives including:

- Why ECHO exists
- Bereavement in the heart community
- Wraparound support from parents, carers, grandparents, and wider family
- Why community support is vital
- Transplant: the conversation
- Living with half a heart and complex health conditions
- Non-surgical pathways and the waiting game



2023 wrap-up

January

Outreach at the PRUH – CEO Sam visited the Princess Royal University Hospital outreach clinic to meet Deborah and Dr Elmasry, Consultant Paediatrician with Expertise in Cardiology, to discuss how to support families in local networks.

February

Our Farm Fun Day at Easton Farm Park was a resounding success with families who loved the lamb feeding, tractor and trailer rides, and nature trails.

Bereavement grants were provided to continue to support parents and carers with the cost of travel to/from hospital or to cover the cost of a funeral or memorial.

March

Online parents' group held with parents/carers, ECHO, and Evelina cardiologists and psychologists to help support children and young people with additional needs.

48 Mother's Day packs – ECHO roped in the help of the Armed Forces programme to deliver 48 packs to carers in hospital.

The Guy's and St Thomas' ICC Paediatric Transition Service – we hosted a meeting at ECHO HQ with the ICC to explore how ECHO can support young people affected by inherited heart conditions.



April

BMX Life Bunny Hop 8 raised over £2,000!

Easter craft packs were delivered for hospital play specialists to use with children in hospital.

ECHO ambassador Charlotte Jane ran the London Marathon for ECHO, after a recent tour with Sam Ryder, raising over £5,000!

May

A Coronation-themed day in hospital put smiles on faces at the Evelina London, as we hosted a day of fun activities, arts and crafts, and a grand royal afternoon tea in collaboration with the play team and medical teams.

ECHO featured on ITV thanks to Amaris, who successfully completed a half marathon bike ride for ECHO, and was then nominated for ITV's Saturday Night Takeaway "unsung hero". She won herself and her family a seat on the plane to Florida after her cycle, which she completed with half a working heart.

June

ECHO Teens Up and Over event saw our teens climbing 52 metres over the O2 and tackling the 30-degree descent, whilst fundraising for us!

ECHO Teens Virtual Film Club collaborates with Young Film Academy hosting “Understanding Documentary Styles” session.

Father’s Day packs created and distributed with the help of Joseph and Joseph and volunteers from MACE Group.

ECHO turned 40!

July

ECHO Teens Heartificial Intelligence exhibition at Science Gallery London displayed an immersive installation, investigating the roles that technology and community play in the healthcare journey of young heart patients. The piece was created in collaboration with Triple Dot Makers and researchers at Wellcome/ESPRC Centre for Medical Engineering. Led by a group of 10 ECHO Teens, they used projection mapping and sensors to create installations that pulse in alignment with the heartbeats of visitors.

August

ECHO Team grows – we welcomed new members of staff including Operations & Development Lead, Cecilia; Fundraising Lead, Rebecca; Communications Administrator, Ethan; and Youth Worker, Andrew.



Heartificial Intelligence exhibit

September

40th birthday celebrations – a brave group of ECHO fundraising superstars dangled in free space from the ArcelorMittal Orbit at an abseil event in London's Olympic Park, a casual 262 feet above ground! Together they raised an incredible £4,000, helping us to provide tailored support where needed.

Hosted virtual drop-in sessions – in collaboration with the cardiology team across Evelina London, Royal Brompton, and CHD network hospitals to provide access to valuable information, support, and the opportunity to connect.

14 Cuski Bertie neonatal positional aids and 5 portable sound machines donated to the Evelina London. As the NHS do not provide these machines, ECHO help to soothe and support the neurodevelopment of preterm infants.

First Aid training for Team ECHO

October

The Health Based Youth Workers’ Conference was attended by Tania and Andrew, our youth work team, to share ideas and best practice with youth workers who support children with a wide range of health conditions. Our youth workers gained insights into different ways of working and found new methods to implement in their own work.

Brianna is chosen by BBC for Children in Need! – ECHO Teen member Brianna is selected by the BBC to join the “Challenge Squad”. Talking to the BBC, mum Sinead recalls the comfort of the advice and support from parents who understood what they were going through, and the project has been a constant in their lives ever since. Through ECHO, Brianna has received practical and emotional support for her complex health conditions and declares she has found somewhere she “truly belongs”.

NatWest Thames Gateway raise £6,400 in a 16-mile walk from their offices in Dartford to the ECHO office in Southwark.

November

Brianna appears on the One Show, explaining the difference ECHO made to her, and dances live on the **Strictly Come Dancing** stage with professional dancer Nadiya Bychkova.

Time to Talk Transition is hosted by ECHO's youth workers and a cardiac nurse specialist, for young people and their parents to learn more about the transition from children's services to adult.

ECHO attend the British Congenital Cardiac Association (BCCA) conference in Bristol, connecting with cardiac associations across the UK including the BCCA, Paediatricians with Expertise in Cardiology Special Interest Group (PECSIG), Congenital Cardiac Nurses Association (CCNA), and other healthcare professionals.

ECHO's diversity ducks were a great hit at BCCA, supporting our inclusion research / Team ECHO at First Aid Training



December

BMX Life Santa Cruise 9 – 740 Santas, elves, reindeers, and Christmas trees hopped on BMX bikes for an 8-mile ride around London, raising over £17,956 for ECHO!

ECHO Christmas Elves delivered Christmas presents to children in hospital, and spread joy through hospital wards, intensive care, and high dependency units, made possible by ECHO's Secret Santa donors and corporate supporters.

ECHO Teens Festive Dinner at Wonderland Soho to connect with friends and enjoy 'fast food heaven' in Soho.

ECHO Teens in-person Festive Fun event, included ice skating at Somerset House and dinner at Tao Tao Ju in Chinatown.

New resource Our Diverse Neighbourhood is launched on the ECHO website, bringing Lambeth and Southwark to patients' bedsides. The resource displays nearby locations like worship buildings, parks, cafes, shops, and provides advice, to make patients and their families experience more comfortable. The project is made possible thanks to funding through the KCL CME community health grants.

***"The need for this resource grew out of conversations with the mother of one of our Muslim member families who described the challenge they faced in finding food to meet their religious and cultural needs and a mother whose son's allergies and dietary requirements caused concern when their children had extended stays at the hospital."** CEO Samantha*

Who we supported and how

ECHO provides support to:



Children and Young People
with heart conditions from birth to 25



Parents/Carers
from prenatal diagnosis and as their child grows up, at times when they need us



Siblings
of someone with CHD from birth to 25



Wider family
who support ECHO members



Professionals
in the Lifelong CHD Network (merged Guys and St Thomas' - Evelina London and Royal Brompton and Harefield CHD networks)



Parents and carers whose children are diagnosed with a heart condition

This year, we hired a new team member: Family & Volunteer Coordinator. Thanks to this new role, we have been able to strengthen our support of young people, parents, carers, and the wider family. Volunteer numbers dropped dramatically over the pandemic, so we prioritised rebuilding and strengthening this vital service.

“I was told to go and get a coffee, that meant taking a lift, at least ten minutes away from my son- no chance.

I felt that as soon as I stepped away from the ward something terrible would happen”



Following the introduction of our Tea Trolley on Sky Ward last year, we established it as a weekly event in the hospital, providing a trolley full of refreshments, treats and ECHO representatives to give parents/ carers and patients time for tea or time to talk. In this discreet and hospitable way, trained staff are on hand to provide psychological first aid to families.

Parents often sit by their child's bedside for between 12 and 24 hours a day, and don't feel confident in taking breaks. ECHO's Tea Trolley takes place on the ward, but gently encourages people to stretch their legs and take

a moment. It also enables ECHO to introduce parents from different beds to each other: this peer-to-peer support is crucial to families experiencing trauma.

We also hosted bespoke cardiac antenatal classes in partnership with the Tower Team midwives at Guy's and St Thomas'.

Younger children

We sent copies of our *Eddie and Friends* magazine to all the network hospitals and provided distraction equipment and activities in the hospital, including cot wedges for comfort after surgery, sound spas for distraction, and sensory lighting for hospital cots and beds.

ECHO Teens

Our full-time youth service ECHO Teens increased in capacity and works hard to connect and support young people and their siblings affected by heart disease. We were delighted to extend the age range of the group from 11-18 up to 25, to accommodate our wonderful

growing community of young people and provide longer to gain confidence in self-management.

Film Club

“From feeling completely alone, she now feels that she belongs, and people understand her. My daughter is even now considering going into youth support work when she is older”
Parent of ECHO Teen member

We continued to run our ECHO Teens Film Club, kicking off with a “Have Your Say” session, to allow space for our teens to share their thoughts and contribute their ideas for the year’s events and activities. We learnt that they would like the film club sessions to focus on the development of the skills required to make films. So, we partnered with the Young Film Academy, the UK’s leading provider of filmmaking courses, to devise and deliver three workshops to upskill them. In September and November, the young people had the opportunity to showcase their skills at the filming of the One Show’s Children in Need campaign. We further facilitated community and connection in December with our *Festive Fun* programme, which included a dinner meet-up, an ice-skating trip, and an online festive-themed escape room.

“Through ECHO Film Club I have gained more confidence in everyday life and have joined in new activities outside and inside of school. As a teenager with CHD, I always find it hard to do things other people do, and ECHO Film Club has helped me realise that even though I have a heart condition it doesn’t define who I am.” *Young person aged 15*

‘Heartificial intelligence’

We were exceptionally proud of our ECHO Teens members who took part in the ‘Heartificial Intelligence’ project supported by King’s College London, investigating the role that technology and community play in the healthcare journey of patients. Nine of our young people collaborated with artist group TripleDotMakers, researchers from the School of Biomedical Engineering and Imaging Sciences, and Wellcome/ESPRC Centre for Medical Engineering to create an interactive installation exhibited at the Science Gallery until January 2024.

Led by ECHO Teens, Heartificial Intelligence uses sensors to create installations that pulse in time with the heartbeats of the visitors, while a sound recording explores themes including trust towards AI in healthcare.

“It was great to work with ECHO Teens, to bring our researchers together with them to co-create this exhibit with TripleDotMakers. A perfect opportunity to platform the voices of the young people.” *Deanne, Wellcome/ESPRC Centre for Medical Engineering*



ECHO Teens celebrate at the Heartificial Intelligence installation



40th Anniversary Filming

Up and Over

We organised our popular annual “Up and Over” event, which sees ECHO Teens climb 52 metres over the O2, and tackle the 30-degree descent. For many young people living with a heart condition, embarking on the physical challenge of climbing the arena can be daunting, but in the right environment, physical activity is possible and should be promoted amongst the adolescent heart community.

A by-product of this event is that many young people take this opportunity to fundraise for ECHO and use their achievements here to inform achievements outside of the ECHO Teens

community. Three young people using this event to complement their participation in the Duke of Edinburgh Scheme. Young people's efforts are celebrated and recognised with an achievement certificate presented to them at the end of the climb.

We were also joined by volunteer from the medical teams working on the cardiac ward in the Evelina London Children's Hospital, the presence of the medical professionals brought an additional layer of support to the day.

“As a paediatric cardiology doctor, it was incredibly refreshing to see the ECHO Teens building their own communication skills, confidence, friendships and just having fun” Dr Ron

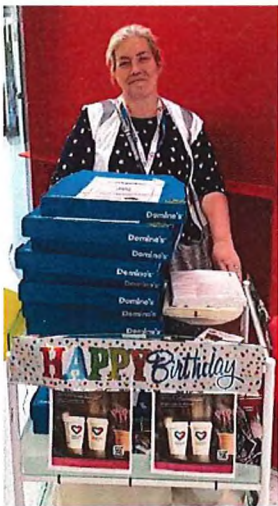
Supporting the whole family

We know from speaking to parents and carers the benefits they experience from meeting other families who have had a child diagnosed with a heart condition, and many people make lifelong friends through ECHO. We hosted in-person community days where families can get together for some fun, adventure, child—friendly activities.

With the Pediatric Cardiology Psychology team from Evelina London, we ran an online group for parents and carers whose child has a heart condition. We also held special events at Ronald McDonald House and Evelina London for families while their child is receiving care.

Support online is growing, including through ECHO's private facebook group, which now numbers 1,600 members. These online resources, including ECHO's website, widen the reach of the charity and provide support outside office hours, which we anticipate will be a growing focus into 2024.

“When we found out about our daughter's condition at 19 months we were terrified. Speaking to other parents did help us.” ECHO member



Support in hospital

ECHO made wellbeing visits to families in hospital and provided an *ECHO Cares* welcome pack for each family, offering immediate practical and emotional support and welcoming them to our community. We also donated small equipment items, arts and crafts packs for families to use with the play team, and Mother's and Father's Day gifts to families.

'Meet Ethel'

Alongside these core services, our Tea Trolley 'Ethel' supplies beverages and snacks to families on Evelina London's Sky ward every Thursday 3pm – 4pm. In February we recruited volunteers to help us expand.

“I use ECHO's parent Facebook group and, on discharge, the nurses provided a pack with information about ECHO and post-surgery. Thank you to all the staff who looked after us.” ECHO member

NHS Staff

Throughout 2023 we continued to award nominated recipients with ECHO Excellence Awards. Nominations of hard-working staff celebrate the difference they make to cardiac families and allow families to show their appreciation. ECHO also supported wellbeing and training events for nurses – often providing parents or patients with lived experience to share their journey.

An 8-year-old ECHO member nominated Ebony, a cardiac nurse on Evelina London's Sky ward:
“She makes you laugh, smile and made me feel really happy. She helped me overcome being scared on the day of the operation. She gave me a pen shaped like a Femur and she is very kind. She made me feel safe to do things even when my mum couldn't and got my sticky stickers off for me. I miss seeing her now I am at home.”

Extending and strengthening our network

In 2023 we sought out opportunities to represent families affected by heart conditions, influence cardiology service design, and let more families know about ECHO's support. We played a key role in representing the family voice in the development of the newly merged Guy's and St Thomas' Lifelong CHD Network (that brings together the Evelina London, the Royal Brompton Hospital and their networks). Our CEO was actively involved in cardiology and healthcare committees, boards and conferences to connect with healthcare professionals. Dr Rigby of Royal Brompton Hospital joined our 'Doodle a Heart' project as part of our 40th anniversary celebrations.

Working with partners

We continued to strengthen our relationship with the Royal Brompton and Harefield, which officially became part of Guy's and St Thomas' NHS Foundation Trust in 2021. We met and opened dialogue with the CEO of the Brompton Fountain to explore opportunities for both charities to maximise support to members of the heart community. Our CEO continues to attend operational and strategic partnership board meetings and committees. We developed our relationship with King's College London's patient engagement teams and made valuable connections with other community groups across Lambeth & Southwark through their introductions. Building relationships with other charities is important to our work, as networking enables us to better signpost families. Our CEO supported Little Hearts Matter, the single ventricle heart condition charity, in the recruitment of their new CEO.

Volunteers

Sameer joined us as part of his work experience and helped design some fantastic ECHO posters. Much to the delight of all concerned, he also brought to life Eddie ECHO, our teddy mascot, during visits to families in hospital.



Jacob, who ran into ECHO after being locked out of his flat, has got involved in fundraising appeal efforts, bringing ECHO over £8,000!

Ben, Amanda, Elissa, and Marion continued to present at antenatal classes every six weeks for families, specifically tailored for parents of children diagnosed with a heart condition antenatally with the Tower Team Midwives.

Building our growing team

During 2023 ECHO doubled its staff team, strengthening our offering of family support work, youth work, volunteering, and fundraising opportunities, and we continue to build close relationships with cardiac teams across the Evelina cardiology hospital network including antenatal, nursing, play therapy, and safeguarding.

Teamwork

Brianna, an ECHO Teens member, was one of our fundraising superstars this year, climbing over the O2 arena and zipping across the UK's longest zip line.



L to R: Volunteers Ethan, Sameer, Dawn and Jacob

“At only a week old I had open heart surgery as I was born with TAPVD. Since then, ECHO has been a huge support system – a light in the dark for both myself and family. They’ve given me a connection to a community. Friends for life.”

“My primary goal in fundraising has always been to give back. For myself, BBC Children in Need and ECHO brought back brightness to my life when I felt most isolated. ECHO has been important in my life for as long as I remember and has support me through, not just my health, but through my education and passions in film and music”

ECHO Teen member, Brianna Brianna was selected to take part in a very special for BBC’s

The One Show, as part of *BBC Children in Need*. The Challenge Squad championed Brianna and 3 other young people to take on a personal challenge and help raise funds for Children in Need, which supports some ECHO’s work. Brianna’s family includes mum, dad and brother- they were amazing getting to filming and helping us maximise the awareness- thank you all!



Rachael skydived for ECHO after we contacted her during her daughter Skylar’s diagnosis and offered our services.

“ECHO has done so much for us they even made sure Santa visited Skylar while she was in ICU and gave her her very first Christmas present” ECHO Parent

9-year-old Amaris had two open heart surgeries before she turned 7, so when she was asked to do a ‘charities’ badge for Brownies, she knew she wanted to “support a charity that helps children like her.” Amaris pledged to raise £150 by completing a half marathon bike ride – after plenty of training, she smashed her target and raised over £1,700! Her fundraising efforts did not go unnoticed and have been shared far and wide, including ITV local news, BBC local radio, and she was even nominated as an unsung hero on Ant and Dec’s Saturday Night Takeaway! Our CEO and Amaris, along with mum, Belinda, spent some time in the park with filming crews to raise awareness.



Amaris and CEO, Samantha

2023: A tale of three Charlottes

Singer-songwriter and ECHO Ambassador **Charlotte Jane** ran the London Marathon and raised an incredible £5,107. Charlotte was running for her nephew Archie who was born with hypoplastic right heart syndrome and underwent open heart surgery at six days old, the first of three surgeries that would take place up until he was four. ECHO are extremely proud to have Charlotte as our ambassador, and thanks to her amazing efforts ECHO can continue to support children like Archie and his family.

We were lucky enough to be nominated by **Charlotte**, a young ECHO member, for her Charity of the Year at school. We presented and held a talk at Great Walstead School, which did some great fundraising for ECHO. It is always lovely to see young people supporting our work and get to know their families and wider community – we got to meet up with her mum and dad Ingrid and Ian for a cuppa too.

ECHO founder Michael Joseph’s daughter **Charlotte** paid a visit to ECHO HQ, and kindly donated a drawing of Michael, which now lives in the *Michael Room*.

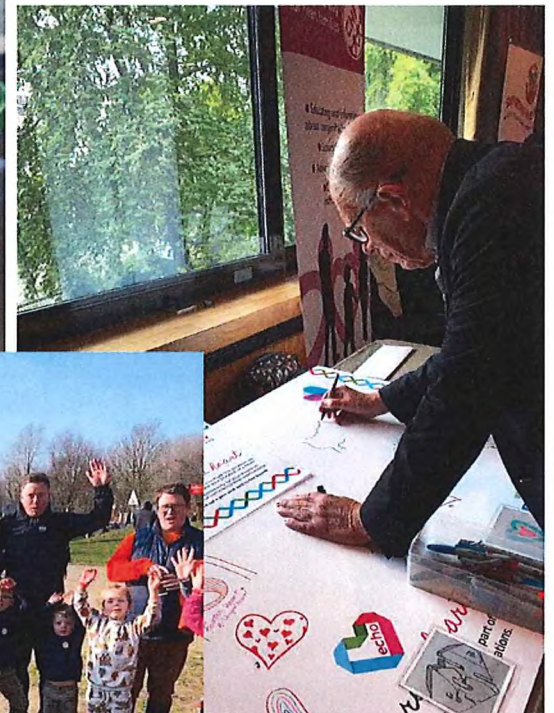
Corporate Support

NatWest teams across London and Kent have been supporting ECHO through some gruelling challenges, such as *Spinathon*; 5k, 10k and 23k group walks; a clifftop hike from Folkestone to Deal; and a 16-mile walk from their Dartford office all the way to ECHO's central London office.

A mixed team including NatWest apprentices also did ECHO Teens' *Up and Over* event in November.

We enjoyed an ongoing corporate partnership with Mace. Sheila and her team help ECHO get Mother's Day and Father's Day packs ready and delivered to parents in hospital, letting them they know we are thinking of them.

Members of recruitment company, Morgan McKinley's, London Team were Santa's Little Helpers in December, wrapping the many treats and gifts provided through the generosity of our Secret Santa Club givers.



Financial Review

Community and events

£6,700 was raised through Facebook fundraising (£10,888 in 2022) while through JustGiving we raised £67,616 (£54,427 in 2022). In total, through digital fundraising, we raised £74,316 (£68,402 in 2022).

Through community and event fundraising, we raised £32,577, through events like the London Marathon (£2,279), ECHO Teens abseil (£3,174), and Wear Red Day (£1,600). Corporates and other organisations raised £47,872 between them. A special thanks to *BMX Life* and all riders who support ECHO annually – in 2023 they raised a total of £20,768.47, including Gift Aid. In terms of individual giving, we received £7,746 in direct debits and £2,988 in standing orders.



Reserves policy 2023

ECHO recognises the amount of reserves we need may vary year on year, COVID-19 brought changes to all charities. It has meant ECHO are looking closely at making sure we can secure our future and support more families. With this in mind, the Trustees have agreed the following reserves policy:

If we are to continue to innovate and provide current services to those we support, additional funding will be necessary to enable these services to be provided.

Planning for unforeseen emergencies and day to day operational costs – ECHO supported more people than over throughout the pandemic, we learnt that we must hold an amount of reserves as a contingency against unforeseen costs for the future.

Uncertainty over future income or ability to raise funds linked to pandemic – As we rebuild our in-person services post Covid-19 ensuring services are robust provides confidence.

Specific costs recognised – ECHO office is scheduled to be demolished meaning we will need to move our operations, and the changes to the London landscape of children's heart surgery through NHS England could double the number of families needing our support.

With this all-in mind the Trustees now want to maintain free reserves in unrestricted funds at a level which equates to approximately 4-9 months of unrestricted charitable expenditure. A new strategy is being put in place, one of expansion of service provision which will increase the range, breadth, and frequency of services we provide to those we support, our investments in the services we provide will benefit more families from across the children's heart community.

ECHO wants to ensure that charity can deliver the work to all who need it, including through another funding crisis.

We have been informed that ECHO's current office will be demolished sometime between 2024/2025. The board has designated £120,000 of our reserves to ensure we will be able to rent a suitable space at full market cost (we currently pay reduced rent), provide a safe place to work for staff and volunteers and the families who need us, as well as staying local to the children's hospital in central London. This figure represents 2-3 years of costs attributed to moving and renting new premises.

Trusts and Foundations

In 2023 we raised a total of £151,930 through Trusts and Foundations

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

- Edith Florence Spencer Memorial Trust
- The Forrester Family Trust
- CME Community Health Fund
- Children in Need
- City Bridge Trust
- Guy's and St Thomas' Trust / Evelina London Children's Charity
- St Mary's Frensham Trust
- Kent Community Fund
- Douglas Arter Foundation
- The Thomas Siveweight Catto Charitable Settlement
- The Hamilton Wallace Trust
- Charles S French Charitable Trust
- The Sir James Roll Charitable Trust
- Vandervell Foundation
- Wallace Bell Charitable Trust
- Costco
- Be Me GSTC
- Garfield Weston Foundation

Risk management

The trustee directors have assessed the risks the charity faces and put in place policies to manage these 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. ECHO has regular staff meetings giving our team the opportunity to review policies, and we have named a trustee as policy lead, which is helpful in presenting policies to the board.

Key Risks and Mitigations

The need for ECHO is growing across all areas of our work. We are seeing more mothers and carers attend ECHO Antenatal Classes, young people taking part in *ECHO Teens*, and families who want support. Some examples of risks identified in 2023 include:

- The need to support almost double the number of members with changes to the London Landscape of children's heart services impacting the number of families joining ECHO
 - We regularly review services to meet the needs of members and keep abreast of future and current changes, identifying how other stakeholders are working through frequent information exchange meetings and presence on decision-making bodies.
- Demand from the network with the potential for an inequitable offer across our region

- To ensure our offer is equitable, regardless of where it is delivered, we liaise closely with the Lifelong CHD Network Leads and place greater emphasis on visits to units and involvement in network events for rapid 'temperature taking' of needs on the ground.
- We have planned to introduce a new database in 2024, to increase ECHO's efficiency and improve relationship management across the supporter base. This should help us to maximise support opportunities, including fundraising and volunteering, to increase the charity's resilience.
- Staff burnout
 - As the needs for our services grow, ECHO is spending time to ensure we are resilient and here for a long time in the future. We hold regular supervision and wellbeing meetings with the team with development, work-life balance, and emotional support conversations at their core.
 - Staff have access to a qualified counsellor for external supervision, which is especially valuable for the front-facing staff who regularly work with families facing uncertainty and trauma.
 - Use of time-off-in-lieu of out of hours working and holiday allowances is actively encouraged, with an understanding that time off is 'protected' from work interruptions.
 - We make time to celebrate achievements and milestones and to build fun into our everyday working patterns.

Safeguarding

Safeguarding is paramount to us, all staff undergo training provided by NSPCC and/or Guy's and St Thomas' NHS Foundation Trust, and we ensure that all volunteers have access to training, policies, and support they need working with children, young people, and vulnerable adults. We have a safeguarding policy and a statement that is assessable via the ECHO website. All trustees, volunteers, and staff attend safeguarding training relevant to their role.

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

ECHO has a skills matrix for our board and will be recruiting according to skills and needs; we have also introduced the role of non-executive advisor to enable us to attract the skills we need on a shorter-term base. We are working towards a "trustee school role" for a younger person enabling us to expand our board, be more inclusive and encourage commitment prior to legal commitment as a trustee. ECHO's priority areas to recruit in the coming years will be a board member Finance (Treasurer), and Special Advisor (young person) and Trustee with expertise in relationship-working. The directors of the company are also charity trustees for the purposes of charity law. The minimum number of trustee directors is 5, and there is no maximum. Questions arising at a meeting are decided by majority votes. The trustee directors meet approximately every 12 weeks and 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.

Plans for the future - What's next? Looking ahead for 2024 we plan to:

- Publish our next five-year strategy
- Engage with the wider ECHO community, with a commitment to being ever more inclusive
- Update the ECHO website and our cardiac support resources, including videos for key milestones in the CHD journey, to give families high quality information that builds their confidence to manage life with CHD
- Recruit more volunteers across a variety of roles, supporting their effectiveness through well-developed and delivered onboarding, training and support

Message from the Chair

I'm proud of what ECHO achieved during 2023, we made material progress in our growth plans which has enabled us to better support our members and create a sustainable future for ECHO for the next 40 years. I'd like to thank our members, the ECHO staff, our volunteers, Fund Raisers, and our Trustees for their continued support of the charity. I take pride in seeing how everyone comes together to support such an important cause.

Declaration

The trustee directors declare that they have approved the trustee directors' report above. Signed on behalf of the charity's trustee directors:



Steve Wood, Chair during 2023



EVELINA CHILDREN'S HEART ORGANISATION
(A company limited by guarantee)

Registered Charity number 1146494

Company Number 7867592

ACCOUNTS FOR THE PERIOD FROM 1 JANUARY 2023 TO 31 DECEMBER 2023

Evelina Children's Heart Organisation Limited
Accounts for the period from 1 January 2023 to 31 December 2023

Charity Name Evelina Children's Heart Organisation Limited
Working Name ECHO
Charity Number 1146494
Company Number 7867592
Registered Office Canterbury House, 1 Royal Street, London. SE1 7LL

Board of Trustee Directors
Patricia Jane Ward
Joanna Eyeson
Alex Bicknell
Stephen Wood Chair
Marc Harry
Lynne Powrie

Independent Accountant Danestone Business Services Ltd
52 Crown Drive, Inverness. IV2 3QG

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

Evelina Children's Heart Organisation Limited
Statement of Financial Activities
For the period from 1 January 2023 to 31 December 2023

	Unrestricted Funds Period Ended 31 December 2023 £	Restricted Funds Period Ended 31 December 2023 £	TOTAL FUNDS Period Ended 31 December 2023 £	TOTAL FUNDS Period Ended 31 December 2022 £
Incoming Resources	(Note 3)			
Donations	195,877	124,905	320,782	282,921
Investment Income	3,380	0	3,380	705
Gift Aid	912	0	912	0
Total incoming resources	<u>200,169</u>	<u>124,905</u>	<u>325,074</u>	<u>283,626</u>
Costs of Providing Charitable Activities	(Note 4)			
Cost of fundraising	71,193		71,193	50,975
Charitable Activities	201,038	82,682	283,720	228,630
Governance	776		776	763
Total Resources expended	<u>273,007</u>	<u>82,682</u>	<u>355,689</u>	<u>280,368</u>
Net movement in funds	<u>(72,838)</u>	<u>42,223</u>	<u>(30,615)</u>	<u>3,258</u>
Reconciliation of funds				
Total Funds brought forward	<u>280,156</u>	<u>35,025</u>	<u>315,181</u>	<u>311,923</u>
Total Funds carried forward	<u>207,318</u>	<u>77,248</u>	<u>284,566</u>	<u>315,181</u>

Evelina Children's Heart Organisation Limited
Balance Sheet as at 31 December 2023

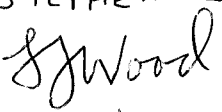
		31 December 2023	31 December 2022
		£	£
Fixed Assets	(Note 5)	8,405	5,495
Current Assets			
Debtors/Prepayments	(Note 6)	5,008	13
Cash at bank and in hand		274,657	310,941
Total Current assets		<u>288,070</u>	<u>316,449</u>
Creditors falling due within one year	(Note 7)	(3,504)	(1,268)
Net Assets		<u>284,566</u>	<u>315,181</u>
Funds of the Charity			
Unrestricted Funds		87,318	160,156
Unrestricted Designated funds	(Note 8)	120,000	120,000
Restricted Funds	(Note 9)	77,248	35,025
Total Funds		<u>284,566</u>	<u>315,181</u>

For the year ending 31 December 2023 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

* The members have not required the company to obtain an audit of its accounts for the year in question in accordance with section 476

* The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts.

These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime

Chair **STEPHEN WOOD**

 Date: **2/9/2024**

Evelina Children's Heart Organisation Limited
Notes to the Accounts

Note 1: Accounting Policies

The principal accounting policies are summarised below. The accounting policies have been applied consistently throughout the period.

Basis of Accounting

The financial statements have been prepared on the basis of the historic cost convention and in accordance with the Companies Act 2006 and the Statement of Recommended Practice - Accounting and Reporting by Charities (SORP 2005) issued in March 2005.

Fund Accounting

Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity. Restricted funds are subjected to restrictions on their expenditure imposed by the donor.

Incoming resources

All incoming resources are recognised once the charity has entitlement to the resources, it is certain that the resources will be received and the monetary value of incoming resources can be measured with sufficient reliability.

Grants and donations are included in the SoFA when the charity has unconditional entitlement to the resources and incoming resources from tax reclaims are included at the same time as the gift to which they relate.

Investment income is included when receivable.

Resources expended

Expenditure is recognised on an accrual basis as a liability is incurred.

Costs of generating funds are those costs incurred in attracting voluntary income.

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its members. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature to support them.

Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include independent examination fees and costs linked to the strategic management of the charity.

All costs are allocated between the expenditure categories of the SoFA on a basis designed to reflect the use of the resource. Costs relating to a particular activity are directly allocated.

Fixed assets

Tangible fixed assets are stated at cost less depreciation. Depreciation is provided at rates calculated to write off the cost

useful life as follows:-

Computer equipment - 33.33% straight line basis

Fixtures & Fittings - 33.33% straight line basis

Note 2: Trustees Remuneration

No remuneration was paid to the trustees in the 12 month period ended 31 December 2023
Expenses of £136.67 were paid

Note 3: Analysis of incoming resources

Voluntary income:

Unrestricted donations

Restricted donations

Investment income:

Bank Interest

Total

Total Funds
12 month period to
31 December 2023
£

196,784

124,905

3,385

325,074

Note 4: Analysis of charitable activities

Back Office/Admin

Volunteers

Information

Member Support

Total

12 month period to
31 December 2023
£

55,499

759

2,675

224,788

283,720

Note 5: Fixed Assets

	<u>Fixed Assets</u>
	<u>£</u>
<u>Cost</u>	
At 1 Jan 2023	11,672
additions	8,781
At 31 Dec 2023	<u>20,453</u>
<u>Depreciation</u>	
At 1 Jan 2023	6,177
Charge 2023	5,871
At 31 Dec 2023	<u>12,048</u>
<u>Net Book Value</u>	
At 1 Jan 2023	5,495
At 31 Dec 2023	<u>8,405</u>

Note 6: Analysis of Debtors/Prepayments

	<u>£</u>
Prepayment : Rent	4,008
Trade Deposit	1,000
	<u>5,008</u>

Note 7 : Analysis of Creditors

	<u>£</u>
<u>Accruals</u>	
Trade creditors	2,229
PAYE, NIC, Pension	1,275
	<u>3,504</u>

Note 8 : Unrestricted Designated Funds

	<u>£</u>
Provison for office space for 3 years as current office to be demolished and rebuilt.	<u>120,000</u>

Note 9 : Ringfenced Income

	<u>£</u>
Balance B/F	35,025
Ringfenced Donations	124,905
Expenditure	(82,682)
Balance C/F	<u>77,248</u>

Management Accounts for 2023

<u>Income</u>	<u>£</u>
Donations	£321,694.00
Interest	£3,380.00
TOTAL INCOME	<u>£325,074.00</u>
<u>Costs</u>	
General Admin	£32,132.00
Fundraising	£17,011.00
Promotional Items	£5,400.00
Staff Costs	£244,102.00
IT Costs	£7,449.00
Charitable Activities	£43,486.00
Volunteer Costs	£759.00
Legal & Governance	£5,350.00
TOTAL COSTS	<u>£355,689.00</u>
Excess Income/Costs	<u><u>-£30,615.00</u></u>



Section A

Independent Examiner's Report

Report to the trustees/directors/ members of

Charity Name EVELINA CHILDREN'S HEART ORGANISATION LIMITED

On accounts for the year ended

31 DECEMBER 2023	
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Charity no.:	1146494	Company no.:	7867592
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Set out on pages

1 - 7	(remember to include the page numbers of additional sheets)
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I report to the charity trustees on my examination of the accounts of the Company for the year ended **DD / MM / YYYY**.

Responsibilities and basis of report

As the charity's trustees of the Company (who are also the directors of the company for the purposes of company law), you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ("the 2006 Act").

Having satisfied myself that the accounts of the Company are not required to be audited for this year under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ("the 2011 Act"). In carrying out my examination, I have followed the Directions given by the Charity Commission (under section 145(5)(b) of the 2011 Act).

Independent examiner's statement

[The company's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of [insert name of applicable listed body]]. Delete [] if not applicable.

I have completed my examination. I confirm that no material matters have come to my attention (other than that disclosed below *) which gives me cause to believe that:

- accounting records were not kept in accordance with section 386 of the Companies Act 2006; or
- the accounts do not accord with such records; or
- the accounts do not comply with relevant accounting requirements under section 396 of the Companies Act 2006 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination; or
- the accounts have not been prepared in accordance with the Charities SORP (FRS102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

** Please delete the words in the brackets if they do not apply.*

Signed: Date:

Name:

Relevant professional qualification(s) or body (if any):

Address:

Section B Disclosure

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

EVELINA CHILDREN'S HEART ORGANISATION LIMITED

England & Wales - Charity number 1146494

Accounts



EVELINA CHILDREN'S HEART ORGANISATION LIMITED

(A Company Limited by Guarantee)

Registered Charity Number 1146494

Company Number 7867592

REPORT OF THE BOARD OF TRUSTEE DIRECTORS

FOR THE PERIOD 1 JANUARY 2022 TO 31 DECEMBER 2022

Evelina Children's Heart Organisation Limited
(A company limited by guarantee)

Report of the Board of Trustee Directors for the Period 1 January 2022 to 31 December 2022

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 Patricia Jane Ward until August 2022 Steve Wood from September 2022
Treasurer Alex Bicknell

Trustees

- Alex Bicknell
- Joanna Eyeson
- Stephen Wood
- Marc Harry
- Jane Ward
- Lynne Powrie (appointed 23 March 2022)

Leavers

- James Pincus (appointed 12 September 2012, resigned 23 March 2022)

Staff

- **Chief Executive** Samantha Johnson
- **Community & Administration Manager** Emma Orpin
- **Fundraising & Development** Kate Smith
- **Community Coordinator** Vashti MacDonald-Clink
- **Youth Worker** Tania Weekes (start date 4 April 2022)

Leavers

- **Head of Operations** Siobhan Morton (17 September 18 - 24 August 22)
- **Impact & Development Lead** Tracey Parry (28 March 22 - 20 October 22)
- **Communications & Volunteering Coordinator** Sinéad Houlihan (17 Sept 18 – 24 Aug 22)

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

Letter from the Chief Executive

ECHO emerged from the constraints of Covid a more resourceful organisation, ready to expand its community of families, partners, staff, and volunteers. Throughout 2022, the charity has extended its geographical base and the range and reach of its services.

By facing head-on, the uncertainties of 2020 and 2021, we have developed resilience to support families and our professional colleagues through individual and collective challenges. This report showcases the highlights of 2022 and sets the scene for the work ahead to reach underserved sections of the congenital heart community.

ECHO's primary focus is always to respond to the needs of children treated for heart conditions within the Evelina London Children's Hospital networks and their families. We are proud to be an independent charity -- we receive no funding from the government or the NHS -- but to best serve our families, we build long-lasting relationships with a wide range of partners. We work to ensure that our contacts with individuals are consistently positive – and, where possible, life-enhancing – professional and effective.

With that focus on the individual in mind, I am delighted to report ways in which we scaled up our offer. During 2022 we:



- Welcomed 83 new families (332 individuals - 163 children) to the ECHO Heart community, bringing the total number of active members to over 8,000.
- Extended the age range for support for children with CHD and their siblings from 0-18 years up to age 25 to give additional time for our young people to grow in confidence, resilience, and skills to flourish in adulthood
- Provided over 900 *ECHO Cares* packs to give comfort and practical help to parents whose children have arrived at the hospital in an emergency or those who stay in hospital for a procedure.
- Offered more opportunities for exchanging information and insights between heart parents by launching an online Forum
- Expanded our Teens' service, investing for the first time in a full-time youth worker, giving more opportunities for our young people to develop their talents, skills, and voices as they had fun together
- Ran more than 25 events that provided connection, challenge, sparkle, and self-discovery both online and in person.





- Introduced the ECHO QR code to the Evelina London & Princess Royal London Hospitals for children's cardiac clinic letters
- Increased our representation for the CHD community at nurse wellbeing days by attending conferences and playing an active role on boards and committees, including the CHD Network PPV Group, Wellcome/EPSRC Centre for Medical Engineering Public Engagement Advisory Board, Cardiac youth worker group, Healthcare youth workers, RBHKHP partnerships.
- Gave wings to creativity through five Teens Virtual Film Club sessions with an average of 6-10 households online each time. We set up the Film Club during lockdown to bring ECHO's young people together online to learn film techniques to create footage about their lives and passions

- Premiered our film *At Home But Not Alone – More Than Our Hearts* in three virtual VIP screenings for young people after 18 months of creating through the Virtual Film Club
- Co-created artwork at the interface between art, AI, and CHD. Our partners from King's College London brought together ECHO Teens with some of its heart researchers, artists, and a patient group to co-create a piece of art that will form part of an exhibition called *AI and Health* at the Science Gallery London for six months in 2023.

As Chief Executive, I am grateful to every person who has given their time, skill, effort, passion, or finances to enable the charity to pre-empt and respond to the needs of children and families affected by congenital heart disease (CHD), acquired and inherited conditions in 2022 and to plan for even more of this vital work for the years to come.

Samantha Johnson, CEO

About ECHO

ECHO supports families affected by children's heart conditions at every stage of their journey, helping from diagnosis (often during pregnancy) through to a child's teenage years and beyond as they transition to adult cardiology services. ECHO connects the children's heart community by bringing together children and young people with heart conditions, their families, and medical professionals. This strong network at all life stages of the child's journey with CHD is often accessed in a crisis and again years later at different milestones. Many of our members regard ECHO as a second family.

Key services

Information and guidance: ECHO provides information and advice via our website, leaflets, social media, newsletters, books for children, and specialist discharge and pregnancy information packs.

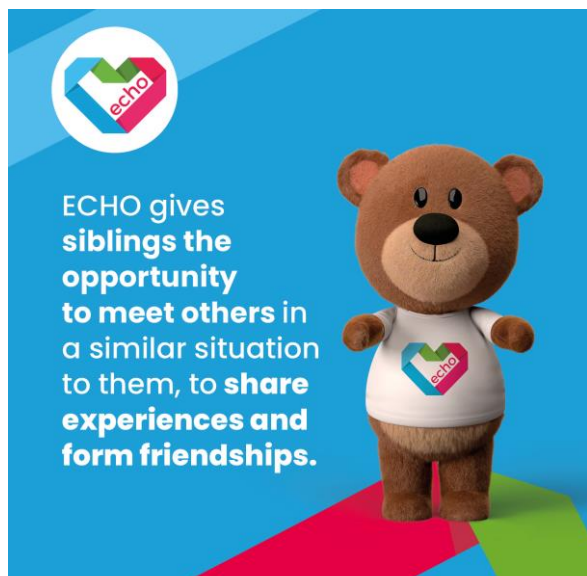
Antenatal classes: ECHO funds bespoke cardiac antenatal classes for parents whose unborn child has been diagnosed with a heart condition.



Parent (or carer)/patient advocacy: ECHO represents parents (or carers) and patients locally and nationally to improve parent or carer/patient experience.

Hospital resources: We redesign and revitalize spaces within Evelina London, including the parent's room and psychology space.

Comfort packs: Packs for parents whose children have arrived at the hospital in an emergency, containing practical help at a time when nothing else is available. Gift packages on Mother's and Father's Day.



Events: Gatherings and activities for children with heart conditions, their parents, and siblings, helping to reduce isolation, promote wellbeing, improve local support networks, and enable families to meet others who are experiencing a similar situation.

Parent-to-Parent support: ECHO organises and trains volunteers who provide emotional support at the hospital, on the telephone, via email, or through organising and participating in local events.

Online support: ECHO manages a closed Facebook group enabling heart parents to meet online and share stories, Happiness Hubs that focus on wellbeing, and a dedicated online ECHO Forum.

ECHO Teens: Information and guidance, fun activities, and helping young people transition to adult hospital services.

Bereavement support: Remembrance gatherings and small bereavement grants.

Toys and crafts: Toys and crafts for children at Evelina London Children's Hospital.

Equipment that cannot be provided by the NHS Small, practical equipment that cannot be funded by the NHS.

Offering support and reassurance for every single member of the family (fathers, mothers, carers, and siblings) in a variety of ways, from information and guidance to gatherings designed specifically for that member of the family.

ECHO Red Letter Days in 2022

January

Winter Walk -- with the marathon, half marathon, and 10k options -- the first of several externally-organised fundraising events throughout the year that gave our supporters a chance to stretch themselves against their own goals for fitness and fundraising.

February

Ziplining to raise awareness at Hangloose Bluewater, England's longest zipline.

March

Mother's Day Packs – carefully put together by volunteers from ECHO who had been through long hospital stays and wanted to give back.

April

BMX Bunny Hop – over 200 BMX riders enjoyed a ride out with a special trip to the children's hospital for an Easter Craft & Egg drop.

May

Up and Over Challenge – Raising the Roof on Transition, with 20 young people plus 20 parents and volunteers. As well as engaging in the physical challenge of climbing over London's O2 arena, other activities gave ECHO's teenage members a chance to shape the new young people's service and to explore their thoughts and feelings about their medical transition. Their conversations revealed that several of the young people had never spoken about the prospect of leaving paediatric care and moving across to adult care. This empowered the group to ask questions they have never asked before and share their worries and anxieties in a safe space, supported by trusted adults and others with shared lived experiences.

June

Father's Day Packs- Put together by a new corporate partner, MACE, in order to give ECHO Dads a little treat made special by the donation from Joseph & Joseph of water bottles.

July

Plans to explore how ECHO could use 3D-printed hearts as a resource in our family room with Nick Byrne (Evelina) and Karen McCarthy (RBH) begun.

August

ECHO's Summer Fun Day BBQ at Ronald McDonald House near the Evelina London Children's Hospital. The event enabled over 100 ECHO members to connect.

"Thank you so much to all the ECHO team and volunteers for today's Summer Fun Day BBQ. We had a wonderful time. It was special to see some of the nurses and doctors that cared for our son and also lovely to connect with other heart families,"

September

World Heart Day Station Collection

October

New Scientist Live Exhibition - made possible through our long-standing and close collaboration with King's College London, this was a rich informal learning opportunity for 10 of our young people.

Family Fun Day at Kent Life Farm. Over 100 people -- 29 families, plus staff, volunteers, and supporters -- came together to explore the farm, carve pumpkins, paint pottery, and enjoy each other's company.

November

Workshop 1 for the Co-production of Art project with Kings College London and 10 ECHO young people

December

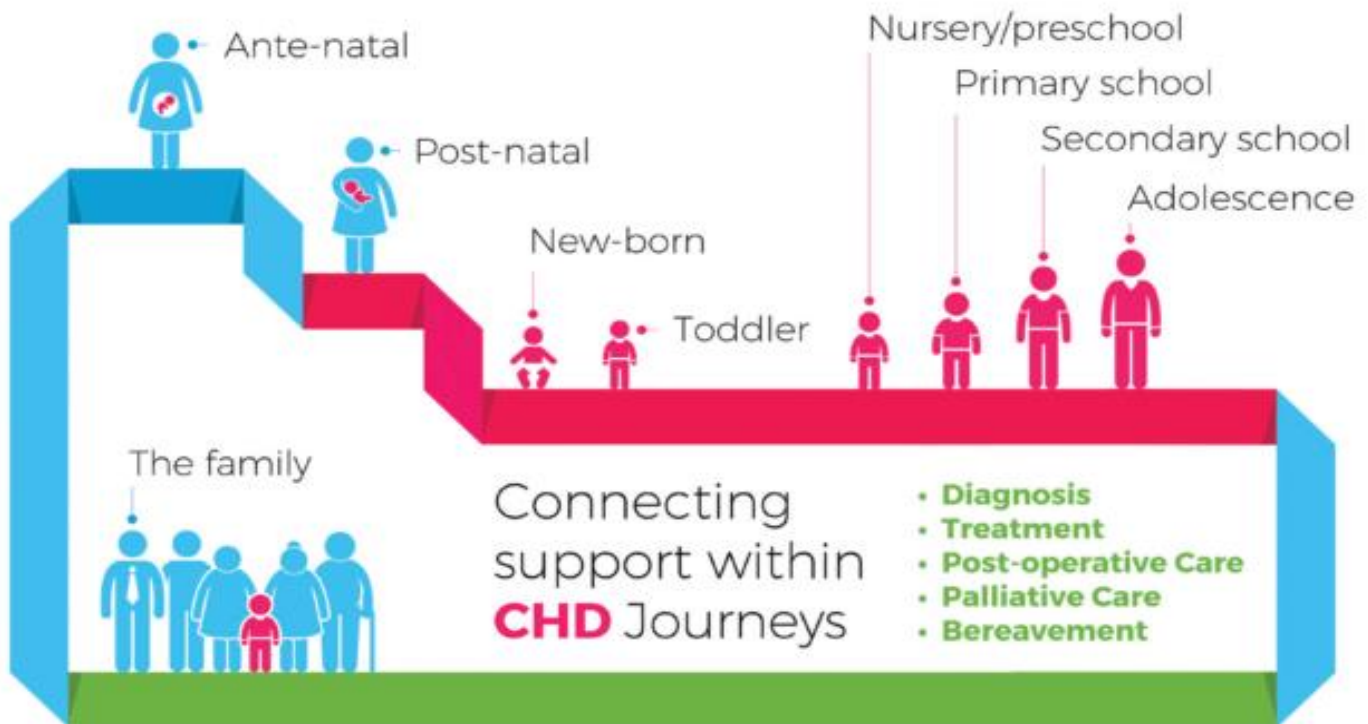
BMX LIFE London Santa Cruise for over 600 people

Stranger Sings theatre trip for twenty 16 to 25 year olds

Online Escape Room for fifteen 11 to 17-year-olds



Who we supported and how



Parents and carers whose children are diagnosed with a heart condition

We are there for families from the moment a diagnosis with the heart health of a baby, child, or young person is suspected. Our wide range of services enables parents, carers, and the wider family to understand medical information in order to make decisions and be as well prepared as possible to support the child and its siblings through procedures, treatments, and growing up with a heart condition.

Before birth

ECHO funds bespoke cardiac antenatal classes for parents whose unborn child has been diagnosed with a heart condition. In partnership with the Tower Team midwives at Guy's and St Thomas', we ran another successful year of online classes every six weeks that were attended, on average, by 15 to 18 couples every session. These explored delivering at a specialist hospital, birth, and after birth. Experienced ECHO heart parents played an active part, providing insight and reassurance from their own experiences, with an opportunity for the class members to share their concerns and ask as many questions as they needed to.

"We had a Zoom class with the Tower team midwives and ECHO, which was so helpful and prepared us for the birth and the baby being taken to NICU," said an ECHO member.

"We went to the ECHO antenatal class, and it was the best meeting I could have gone too as it gives you lots of information about what to expect when you go into labour, who will be in the room, and it also takes you around the maternity unit and the special care unit, so it's not overwhelming if your baby needs to go there after birth," ECHO member.

During childhood

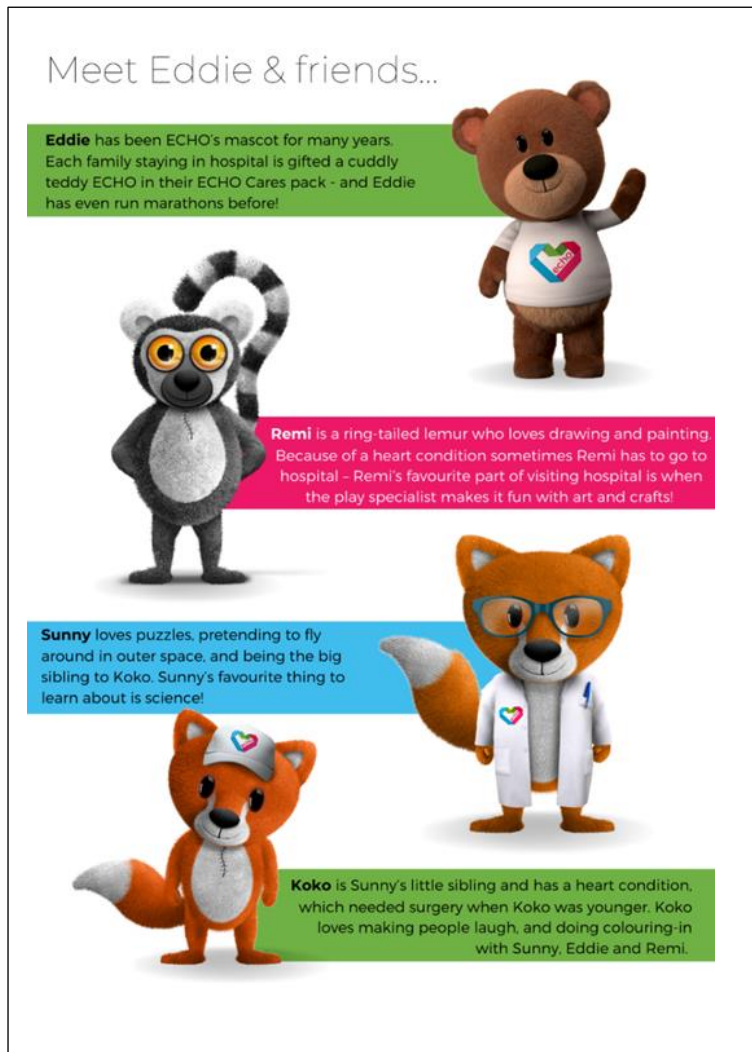
Our Paediatric Cardiology Parents' Group, run in partnership with the cardiac psychology team, covers topics to help parents support their children who are living with a heart condition. The group met eight times online, covering topics including promoting positive behaviour,

managing the transition to young adulthood and adult services, and strategies to support children and young people with additional or neurodiversity needs.

Younger children

Eddie & Friends magazine is designed for children aged 10 and under with heart conditions who are patients in the hospital and their siblings. The 15-page magazine is packed with activities, puzzles, and jokes to help keep children entertained and offer some comfort and distraction while they recover from surgery or treatment. Each magazine also comes with 24 stickers. In 2022, we were thrilled to introduce Eddie ECHO's friends, Sunny and Koko – three new characters who will feature in our future resources.

Meet Eddie & friends...



Eddie has been ECHO's mascot for many years. Each family staying in hospital is gifted a cuddly teddy ECHO in their ECHO Cares pack - and Eddie has even run marathons before!

Remi is a ring-tailed lemur who loves drawing and painting. Because of a heart condition sometimes Remi has to go to hospital - Remi's favourite part of visiting hospital is when the play specialist makes it fun with art and crafts!

Sunny loves puzzles, pretending to fly around in outer space, and being the big sibling to Koko. Sunny's favourite thing to learn about is science!

Koko is Sunny's little sibling and has a heart condition, which needed surgery when Koko was younger. Koko loves making people laugh, and doing colouring-in with Sunny, Eddie and Remi.

Eddie & Friends magazine has been written with the help of Cecilia Adamou, a young writer who grew up with a heart condition and has had a heart transplant. Cecilia has been an ECHO member since she was born and continues to be a big supporter of the charity.

"In addition to being a relaxing distraction *Eddie & Friends* includes practical resources to help children under 10 talk with their grown up or cardiac team about how they are feeling, helping to alleviate some of the worry we know comes with staying in hospital. I'd like to thank those young patients, parents and carers who contributed and helped produce the magazine"

Samantha Johnson, ECHO Chief Executive

Eddie & Friends magazine was available for free from March 2022 for all children with heart conditions and their siblings who are inpatients at Evelina London including the cardiac Sky ward, PICU and those visiting the Walrus Outpatients Department. Copies have also been distributed across 27 network hospitals.

ECHO Teens

A key focus for ECHO in 2022 was to enrich and expand the ECHO Teens service offer to support our young people in their personal, social, and emotional development. Through time together in fun group activities and one-to-one support, our young people built their communication skills and confidence to ask questions, make decisions and manage their condition independently.

"ECHO has given me the confidence to find who I am," ECHO Teen member.

In April 2022, ECHO hired a full-time youth worker for the first time. During her first six months she compiled a community profile to give us a clearer understanding of the needs, interests and priorities of our young people, and workshops with them directly informed the design of

the service offer, including a greater emphasis moving forward on physical activity and sports, wellbeing and mental health and transition to adult services.



Film Club

We heard from our young people that the online support we provided made things easier for them, as they were still concerned about the pandemic and had to catch up with school and clubs.

We decided to continue with our very popular online film club for young people aged 11-18 years affected by heart conditions in order to provide young people affected by heart conditions, both patients and their siblings, a safe space to develop new skills whilst learning about self, others, and

the world around them through the mediums of film and the arts. All members of the ECHO Teens film club receive a Film Club pack in the post, including a tripod and smartphone lens filters, plus their own ECHO Teens t-shirt and tote bag. During the sessions, ECHO teen members took part in live recordings showing off their talents, voices, skills, and experiences.

The thoughts and feelings of the group were captured and produced in a short film, *Home But Not Alone – More Than Our Hearts*, which will be shared with the wider heart community at our VIP online film premiere in November 2023.



“During the lockdown, it was a bit of a hard time, and I kept on thinking back to when umm, my brother was in the Evelina with his heart condition and er, I was struggling with it a little bit, but I found the online community, just to see everyone is fine, it’s just good to see everyone is thriving with or without a heart condition.”
ECHO Teen member, who at the end of November, offered to become a volunteer helping to develop our offering to young people.

The whole family



Community events

Our community events give opportunities for families to understand and support each other and enable more connections for ECHO teens and siblings of children with heart conditions to take part in fun activities such as urban art together, exploring self and identity.

“ Meeting other families who have been through a similar experience allowed me not to feel alone. In turn, I can identify with how it feels to go through this news and how we adapted as a family,” ECHO member.
“We love the social side of ECHO, questions answered by everyone’s experiences and a friendly face to just chat to is perfect,”
ECHO member.

Support in hospital

We provide equipment to make hospital stays more comfortable and bedside support through arts and crafts and activities on the ward. In 2022, we introduced a new ECHO Tea Trolley on wards in the Evelina Hospital. This gives a natural way of offering psychological first aid alongside much-appreciated beverages and treats.

Diversity and inclusivity

We have continued the conversation started in our inclusivity project with Guy's and St Thomas' and the Royal Brompton hospitals, in which over 100 families joined us in person to discuss what was important to them. ECHO members shared how hard it was for them to access Halal food and disability- and neurodiversity-friendly activities in the local area around the hospital. On the basis of these findings, in their 2022 Strategy review, ECHO's Trustees committed to prioritising diversity and inclusivity in the charity's future approaches and service offers.

NHS staff

Relationships with cardiac teams at local hospital across the CHD network developed throughout the year by our roles on boards, committees and by team ECHO going on the road and meeting with local NHS teams across Level 1 and 2 hospitals. Special thanks to the Princess Royal University Hospital (Orpington), the Royal Alexander Children's Hospital (Brighton), and Watford General (Watford), whose medical teams accepted many copies of *Eddie ECHO & Me* for their young heart patients, gave us tours of the facilities and welcomed our youth worker to a transition clinic. A special mention and thanks to the administration and secretarial teams who have also helped to ensure the ECHO QR code appears on the bottom of children's cardiac appointment letters, meaning families treated locally can also access ECHO's support.

Throughout 2022 we continued to award-nominated recipients with ECHO Excellence Award. These are unique to the cardiology departments across the Evelina London, Royal Brompton Hospital, and their networks and nominations arrived from parents, carers, patients & NHS colleagues to celebrate the difference that they make to cardiac families.

Winner of January 2022: Kirsty Stewart Paediatric Cardiology Registrar

"Kirsty is very kind and caring and meticulous. She pays close attention to caring for the whole family not just the patient, and goes above and beyond. She is often working late to make sure everything is complete and supports the SHOs well too." ECHO member

Our wellness days and involvement in staff wellbeing days allow us to present ECHO to the nursing teams and provide patient and parent feedback to the cardiac teams that would not be available within the NHS. In 2022, we saw increased referrals after nurse wellbeing days, and we plan to extend this collaboration to specialist midwives in the future.



Teamwork at every level

Volunteers

Against the trend of growth across many areas of the charity, ECHO – in common with many not-for-profit organisations -- saw a huge decline in volunteers. Our numbers reduced by 89% from 72 – 8 people because, during the pandemic, we had to stop face-to-face volunteering. Those who were able to help us online remained and provided key support to our communications, merchandise, and online support groups.

“It is lovely to have a wealth of experience in our team, and volunteers often provide an independent view on the work we are doing; we want to build a community of volunteers providing in hospital, community, admin and event support and thank everyone who gives us time” Samantha Johnson, ECHO CEO

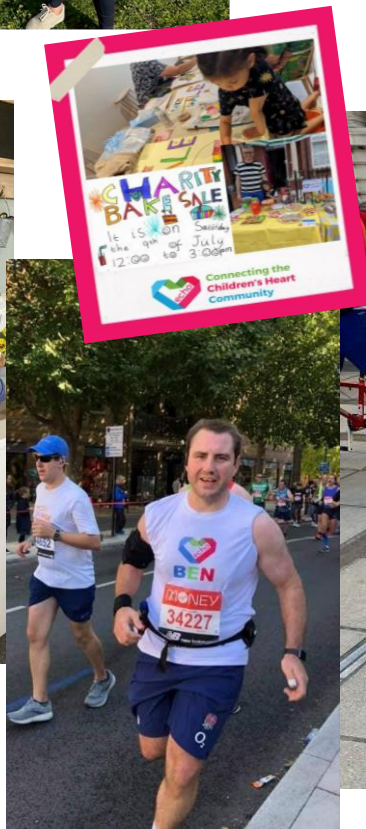
In 2022, thanks to all our volunteers -- like those whose contributions are shown below -- we were able to continue with ECHO Ante Natal classes, provide ECHO Teens events, run a small merchandise shop, update websites and social media, and send out fundraising appeals.

Jacob: Whilst looking at recruitment, training, and retention on one day we recruited Jacob. He was locked out of his home near the ECHO office. Needing to use a phone, he found us by chance and liked what we did. Since then, Jacob has been a regular fundraising volunteer and will move into hospital support soon.



Dawn ensures the ECHO shop is functioning, the fundraisers are contacted and our care packs are delivered, Dawn also enjoys visits to the ECHO office. And keeps stock current.

Marion has been volunteering for over 10 years and has focused time this year on the Ante Natal Classes and on telephone support, Marion has lived experience of congenital heart conditions and as her own family grow into adulthood Marion dedicates time supporting those families entering the children's heart community.



Jean – Marie has kept our social media current and has worked from the USA and throughout her studies, with online and hybrid working, we have learned a lot from each other.

ECHO Ambassador: CHARLOTTE

Charlotte Jane, a singer, and songwriter, is still very much an active supporter of ECHO, helping to increase awareness of congenital heart disease and raising vital funds for our charity. Her nephew, Archie, was diagnosed with congenital heart disease and required heart surgery at just six days old, inspiring her song 'All My Life'. Charlotte has been training for her first London Marathon Place in April 2023

"I've been wanting to do something for a while to raise some more money for the charity and next year's marathon felt especially apt as not only is Archie due to have his big heart operation soon but it's also ECHO's 40th birthday.

Health and care professionals

We have close links with the teams who support ECHO children and their families throughout Guy's and St Thomas' NHS Foundation Trust, at the Evelina London Children's Hospital and St Thomas' Hospital, Royal Brompton Hospital and Guy's Hospital. In 2022, we particularly strengthened our collaboration with Play Therapists and the Psychology Team through the design of the Lodge in outpatients, a space both teams use with cardiac patients.

Mirroring the work of our NHS colleagues managing the merger of Guy's and St Thomas' and the Royal Brompton and Harefield hospitals, in 2022, ECHO laid foundations to work more closely with the Brompton Fountain Charity in order to provide continuity of high-quality support for families during service changes set out by NHS England.

Researchers

Our close collaboration with nearby centres of excellence in research and biomedical engineering at King's College London opened up opportunities for our young people to take part in activities featuring leading-edge science and creative arts, including New Scientist Live and the Co-Production of art for the AI and Health exhibition at the Science Gallery London.

Charities

We continued to collaborate closely with other children's heart charities, including Tiny Tickers, Little Hearts Matter, Young Hearts, CHF, and adult heart charity The Sommerville Foundation, Ronald McDonald House and the National Council for Child Health and Well-being

Corporate support

MACE corporate provided volunteers to help young people climb up and over of the O2, they also helped pack special packs for families – they are looking at ways to work with ECHO and we are excited about what opportunities we can provide. A special thanks to our corporate friends who provide excellent services at discounted rates.



Financial Review

Community and individuals

£10,888 was raised through Facebook fundraising (£22,876 in 2021) while through JustGiving we raised £57,437 (£47,854.59 was raised in 2021) and £77 via Much Loved. In total, through digital fundraising, we raised: £68,402 (£70,730.59 in 2021).

Heart Month (February) In total, we raised £10,536.72 (£1,100 in 2021). Thanks to individuals, schools, companies, and everyone who wore red

BMXLife London Santa Cruise In total, we raised £15,531.83. A special thanks to BMX Life and all riders who support ECHO annually

Reserves policy 2022

ECHO recognises that the number of reserves we need may vary year on year, and COVID-19 brought changes to all charities. It has meant ECHO is looking closely at ensuring we can secure our future and support more families. The Trustees have agreed on the following reserves policy.

If we continue to innovate and provide & current services to those we support, additional funding will be necessary to enable these services to be provided.

Planning for unforeseen emergencies and day-to-day operational costs: ECHO supported more people than over throughout the pandemic; we learned that we must hold reserves as a contingency against unexpected expenses for the future.

Uncertainty over future income or ability to raise funds linked to the pandemic: As we rebuild our in-person services post Covid-19 ensuring vital services provide confidence.

Specific costs recognised: ECHO office plans to be demolished, meaning we must move our operations. Also, the changes to London landscape of children's heart surgery through NHS England could double the number of families needing our support.

With this all-in mind, the Trustees now want to maintain free reserves in unrestricted funds at a level of approximately four to nine months of public charitable expenditure.

The board are reviewing our reserves on a regular basis and will designate funds for urgent items when appropriate.

A new strategy is being put in place, expanding service provision, which will increase the range, breadth, and frequency of services we provide to those we support; our investments in the services we provide will benefit more families from across the children's heart community.

ECHO wants to ensure the services and charity can deliver the work to all who need it as well in case of another funding crisis.

Trusts and Foundations

We have worked hard to build relationships with our funders and have had some positive multiyear funding. As a result, through Trusts and Foundations, ECHO raised £153,000 in 2022. We will continue to build on our relationships as well as reaching out to new Trusts as ECHO grows.

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

- The Basil Samuel Charitable Trust
- Charles S French Charitable Trust
- Arnold Clark Community Fund
- National Lottery Community Fund
- Blakemore Foundation
- BBC's Children in Need

- Tesco Bags of Help
- Garfield Weston Foundation
- SJP Foundation
- Kent Community Foundation
- TK Max Foundation
- Childwick Trust

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. In 2019, we worked with Tom Searle of Britrisk Safety Limited to run risk assessment training to ECHO staff and reviewed our Health and Safety & organisation's Risk Policy, so we regularly update and review these policies.

ECHO has regular staff meetings giving our team the opportunity to review policies, and we have named a trustee as policy lead- this is helpful when presenting policies to the board.

Key Risks and Mitigations

The need for ECHO is growing across all areas of our work. We are seeing more mothers and carers attend ECHO Antenatal Classes, young people taking part in *ECHO Teens*, and families who want support. Some examples of risks identified in 2022 include:

- *The need to support almost double the number of members with changes to the London Landscape of children's heart services impacting the number of families joining ECHO – We regularly review services to meet the needs of members and keep abreast of future and current changes to how other stakeholders are working through frequent information exchange meetings and presence on decision-making*
- *Staff burnout – We ensure our team are supported through professional supervision, 1:1's, and staff wellbeing. The expansion of the leadership team projected in 2023 will offer more capacity for workload management, coaching, and reflective practice.*
- *The Volunteer Co-ordinator role was respecified in 2022 to redevelop the volunteer network.*
- *Planned investment in ECHO's database infrastructure will enable better relationship management across the supporter base, including volunteers.*

As the needs for our services grow, ECHO is spending time to ensure we are resilient and here for a long time in the future.

Safeguarding

Safeguarding is paramount to us, all staff undergo training provided by NSPCC or GSTT, and we ensure that all volunteers have access to training, policies, and support they need working with children, young people, and vulnerable adults. We have a safeguarding policy and a statement that is assessable via the ECHO website. All trustees, volunteers, and staff attend safeguarding training relevant to their role.

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

ECHO has a skills matrix for our board and will be recruiting according to skills and needs; we have also introduced the role of non-executive advisor to enable us to attract the skills we need on a shorter-term base.

ECHO's priority areas to recruit in the coming years will be a board member Finance (Treasurer), and Special Advisor (young person).

The directors of the company are also charity trustees for the purposes of charity law. The minimum number of trustee directors is 5, and there is no maximum. The trustee directors can be appointed in a 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.

Plans for the future - What's next?

Looking ahead for 2023, we plan to:

- Review our services and ensure families needs are met
- Develop and expand our staff team
- Introduce a leadership team
- Produce a resource for teens aged 11-17
- Upskill our board & Staff team
- Focus on governance training and board development
- Update Eddie Echo and Me book with new branding
- Review our website, language, and communications to be more inclusive of congenital and acquired conditions.
- Prepare to reinstate our volunteer service fully.
- Develop our work on diversity and inclusivity.
- Plan to celebrate and increase awareness and fundraising activity over our 40th birthday in 2023.

Declaration

The trustee directors declare that they have approved the trustee directors' report above.
Signed on behalf of the charity's trustee directors:

Jane Ward & Steve Wood, Chairs during 2022

EVELINA CHILDREN'S HEART ORGANISATION

(A company limited by guarantee)

Registered Charity number 1146494

Company Number 7867592

ACCOUNTS FOR THE PERIOD FROM 1 JANUARY 2022 TO 31 DECEMBER 2022

Evelina Children's Heart Organisation Limited
Accounts for the period from 1 January 2022 to 31 December 2022

Charity Name Evelina Children's Heart Organisation Limited
Working Name ECHO
Charity Number 1146494
Company Number 7867592
Registered Office Canterbury House, 1 Royal Street, London. SE1 7LL

Board of Trustee Directors

James Pincus Resigned 23 March 2022
Patricia Jane Ward
Joanna Eyeson
Alex Bicknell
Stephen Wood Chair
Marc Harry
Lynne Powrie Appointed 23 March 2022

Independent Accountant

Danestone Business Services Ltd
52 Crown Drive, Inverness. IV2 3QG

Bank

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

Evelina Children's Heart Organisation Limited
Statement of Financial Activities
For the period from 1 January 2022 to 31 December 2022

	Unrestricted Funds Period Ended 31 December 2022 £	Restricted Funds Period Ended 31 December 2022 £	TOTAL FUNDS Period Ended 31 December 2022 £	TOTAL FUNDS Period Ended 31 December 2021 £
Incoming Resources				
	(Note 3)			
Donations	129,936	152,985	282,921	290,115
Investment Income	705	0	705	42
Job Retention Grant & SSP	0	0	0	58
Total incoming resources	<u>130,641</u>	<u>152,985</u>	<u>283,626</u>	<u>290,215</u>
Costs of Providing Charitable Activities				
	(Note 4)			
Cost of fundraising	50,975	0	50,975	44,021
Charitable Activities	99,670	128,960	228,630	173,639
Governance	763	0	763	763
Total Resources expended	<u>151,408</u>	<u>128,960</u>	<u>280,368</u>	<u>218,423</u>
Net movement in funds	<u>(20,767)</u>	<u>24,025</u>	<u>3,258</u>	<u>71,792</u>
Reconciliation of funds				
Total Funds brought forward	<u>300,923</u>	<u>11,000</u>	<u>311,923</u>	<u>240,131</u>
Total Funds carried forward	<u>280,156</u>	<u>35,025</u>	<u>315,181</u>	<u>311,923</u>

Evelina Children's Heart Organisation Limited
Balance Sheet as at 31 December 2022

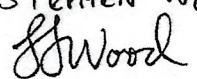
		31 December 2022	31 December 2021
		£	£
Fixed Assets	(Note 5)	5,495	785
Current Assets			
Debtors/Prepayments	(Note 6)	13	13
Cash at bank and in hand		310,941	319,218
Total Current assets		<u>316,449</u>	<u>320,016</u>
Creditors falling due within one year	(Note 7)	(1,268)	(8,093)
Net Assets		<u>315,181</u>	<u>311,923</u>
Funds of the Charity			
Unrestricted Funds		160,156	300,923
Unrestricted Designated funds	(Note 8)	120,000	0
Restricted Funds	(Note 9)	35,025	11,000
Total Funds		<u>315,181</u>	<u>311,923</u>

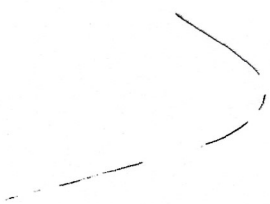
For the year ending 31 December 2022 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

* The members have not required the company to obtain an audit of its accounts for the year in question in accordance with section 476

* The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts.

These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime

Chair **STEPHEN WOOD**

 Date: 08/09/23



Evelina Children's Heart Organisation Limited
Notes to the Accounts

Note 1: Accounting Policies

The principal accounting policies are summarised below. The accounting policies have been applied consistently throughout the period.

Basis of Accounting

The financial statements have been prepared on the basis of the historic cost convention and in accordance with the Companies Act 2006 and the Statement of Recommended Practice - Accounting and Reporting by Charities (SORP 2005) issued in March 2005.

Fund Accounting

Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity. Restricted funds are subjected to restrictions on their expenditure imposed by the donor.

Incoming resources

All incoming resources are recognised once the charity has entitlement to the resources, it is certain that the resources will be received and the monetary value of incoming resources can be measured with sufficient reliability.

Grants and donations are included in the SoFA when the charity has unconditional entitlement to the resources and incoming resources from tax reclaims are included at the same time as the gift to which they relate.

Investment income is included when receivable.

Resources expended

Expenditure is recognised on an accrual basis as a liability is incurred.

Costs of generating funds are those costs incurred in attracting voluntary income.

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its members. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature to support them.

Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include independent examination fees and costs linked to the strategic management of the charity.

All costs are allocated between the expenditure categories of the SoFA on a basis designed to reflect the use of the resource. Costs relating to a particular activity are directly allocated.

Fixed assets

Tangible fixed assets are stated at cost less depreciation. Depreciation is provided at rates calculated to write off the cost useful life as follows:-

Computer equipment - 33.33% straight line basis

Fixtures & Fittings - 33.33% straight line basis

Note 2: Trustees Remuneration

No remuneration was paid to the trustees in the 12 month period ended 31 December 2022.
No expenses were paid during the period.

Note 3: Analysis of incoming resources

Voluntary income:

Unrestricted donations

Restricted donations

Investment income:

Bank Interest

Total

Total Funds
12 month period to
31 December 2022
£

130,026

152,895

705

283,626

Note 4: Analysis of
charitable activities

Back Office/Admin

Volunteers

Information

Member Support

Total

12 month period to
31 December 2022
£

54,469

1,452

917

171,792

228,630

Note 5: Fixed Assets

	<u>Fixed Assets</u>
	<u>£</u>
<u>Cost</u>	
At 1 Jan 2022	4,017
additions	7,655
At 31 Dec 2022	<u>11,672</u>
 <u>Depreciation</u>	
At 1 Jan 2022	3,232
Charge 2022	2,945
At 31 Dec 2022	<u>6,177</u>
 <u>Net Book Value</u>	
At 1 Jan 2022	785
At 31 Dec 2022	<u>5,495</u>

Note 6: Analysis of Debtors/Prepayments

	<u>£</u>
Prepayment :2023 Confirmation statement	<u>13</u>

Note 7 : Analysis of Creditors

	<u>£</u>
Accruals	
Trade creditors	720
PAYE, NIC, Pension	548
	<u>1,268</u>

Note 8 : Unrestricted Designated Funds

	<u>£</u>
Provison for office space for 3 years as current office to be demolished and rebuilt.	<u>120,000</u>

Note 9 : Ringfenced Income

	<u>£</u>
Balance B/F	11,000
Ringfenced Donations	152,985
Expenditure	(128,960)
Balance C/F	<u>35,025</u>



Section A

Independent Examiner's Report

**Report to the
trustees/directors/
members of**

EVELINA CHILDREN'S HEART ORGANISATION LIMITED

**On accounts for the year
ended**

31 DECEMBER 2022

Charity no.:

1146494

Company no.:

7867592

Set out on pages

1-7

**Responsibilities and
basis of report**

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31/12/2022.

As the charity's trustees of the Company (who are also the directors of the company for the purposes of company law), you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ("the 2006 Act").

Having satisfied myself that the accounts of the Company are not required to be audited for this year under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ("the 2011 Act"). In carrying out my examination, I have followed the Directions given by the Charity Commission (under section 145(5)(b) of the 2011 Act).

**Independent
examiner's statement**

The company's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of The Institute of Chartered Accountants in England and Wales.

I have completed my examination. I confirm that no material matters have come to my attention which gives me cause to believe that:

- accounting records were not kept in accordance with section 386 of the Companies Act 2006; or
- the accounts do not accord with such records; or
- the accounts do not comply with relevant accounting requirements under section 396 of the Companies Act 2006 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination; or
- the accounts have not been prepared in accordance with the Charities SORP (FRS102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed: Melza H. Linfield

Date: 07/08/2023

Name: MELZA H LINFIELD FCA

Relevant professional qualification(s) or body (if any):

ICAEW

Address:

DANESTONE BUSINESS SERVICES LIMITED

52 CROWN DRIVE

INVERNESS, IV2 3QG

Section B

Disclosure

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

[Empty disclosure box]

EVELINA CHILDREN'S HEART ORGANISATION LIMITED

England & Wales - Charity number 1146494

Accounts

EVELINA CHILDREN'S HEART ORGANISATION LIMITED

(A Company Limited by Guarantee)

Registered Charity Number 1146494

Company Number 7867592

REPORT OF THE BOARD OF TRUSTEE DIRECTORS

FOR THE PERIOD 1 JANUARY 2021 TO 31 DECEMBER 2021

Evelina Children's Heart Organisation Limited

(A company limited by guarantee)

Report of the Board of Trustee Directors for the Period 1 January 2021 to 31 December 2021

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 Jane Ward

Trustees

- James Pincus
- Patricia Jane Ward
- Alex Bicknell
- Joanna Eyeson
- Stephen Wood
- Marc Harry

Staff

- Chief Executive Samantha Johnson
- Community & Administration Manager Emma Orpin
- Head of Operations Siobhan Morton
- Communications & Volunteering Coordinator Sinéad Houlihan
- Fundraising & Development Lead Kate Smith
- Vashti MacDonald-Clink, Community Coordinator **(started July 2021)**

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



**Connecting the
Children's Heart
Community**

Letter from Chief Executive

As a charity, COVID-19 continued to impact how, where and when we could deliver our services and volunteering opportunities in 2021.

During the past year, we have seen families struggle with their child's medical care; the impact of the pandemic; their mental health and feelings of isolation. We continued providing online and telephone support to ECHO families, while welcoming new members digitally into our online community group and where possible, supporting families in-person.

We were pleased to continue supporting important research including our partnership with the Heart Siblings Impact Study School of Health and Social Care at London South Bank University, and research into 3D heart models and how art connects with science at Kings College London – both will have a direct impact on the ECHO community in the future.

We introduced new characters to the ECHO charity brand, a ring-tailed lemur, a fox and a sibling join Eddie ECHO bear across our children's resources. These characters will help us to share the stories of the ECHO heart community and reflect the significance of siblings throughout the heart journey, as well as those with chest scars from heart surgery.

We have represented families across our community to improve safety, quality of care, and patient experience across various boards and committees and thank those parents who have given us feedback to take forward.

All our services are free for families to access, including membership to ECHO, this allows us to work with families from diverse communities and ensures that our services are openly available to all families affected by children's heart disease when every they need us.

ECHO want to pass on our thanks to everyone who has helped our charity support families affected by children's heart conditions throughout 2021. The pandemic demonstrated the strength of our community - we needed to work together to raise the funds, awareness needed to support those who needed us and together we have done just that.

Whatever you did for our charity in 2021, we appreciate you and know that without your support we could not be there when families need us.

Thank you.

- ***Samantha Johnson, ECHO Chief Executive***

Our mission, vision and values:

- Mission: to support children affected by heart disease & treated by the Evelina London Children's Hospital networks, and their families.

- Vision: a world where the emotional, social, financial and medical needs of heart families are met.
- Values: Resilient, Empowering, Supportive, Open & Honest, Resourceful, Impactful

About ECHO:

ECHO supports families affected by children's heart conditions, 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. 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 we support:

- Children and young people with heart conditions from birth to 19
- Parents/Carers diagnosed either prenatally or during childhood throughout their child's life, at times when they need us
- Siblings of those with heart conditions, from birth to 19 living with a heart child
- Wider family who support ECHO members
- Professionals surrounding families at the Evelina London, Royal Brompton and networks

How ECHO supports families affected by children's heart conditions:

- Information & Guidance: ECHO provides information and advice via our website, leaflets, social media, newsletters and books for children.
- Antenatal classes: ECHO funds bespoke cardiac antenatal classes for parents whose unborn child has been diagnosed with a heart condition.
- Parent/Patient advocacy: ECHO represents patients and parents locally and nationally to improve patient/carer experience, campaign for improvements to government benefits as well as act as an objective partner for families with queries regarding their child's care.
- Hospital Resources: New spaces in hospital: redesigning & revitalising spaces within Evelina London including the parent's room and new psychology space
- Discharge & Pregnancy packs: specialist information packs.
- Comfort packs: Packs for parents whose children have arrived at hospital in an emergency, containing practical help at a time when nothing else is available.
- Gift packages on Mother's and Father's Day
- Events: Events for heart children, their parents and siblings, helping to reduce isolation, promote wellbeing, improve local support networks and enable families to meet others who are experiencing a similar situation.

- Parent-to-Parent Support: ECHO organises & trains volunteers who provide emotional support at hospital, on the telephone, via email or through organising & participating in local events.
- Online forum: ECHO manages a closed Facebook group enabling heart parents to meet online and share stories.
- Support for Dads: Documentary film offering advice and reassurance to fathers and male carers of a child with a heart condition.
- Support for Siblings: Annual ECHO Sibling Day gathering, plus information and guidance designed specifically for siblings.
- ECHO Teens: information & guidance, fun activities and helping young people transition to adult hospital services.
- Bereavement Support: Remembrance gatherings and small bereavement grants.
- Toys & Crafts: Toys and crafts for children at Evelina London Children's Hospital.
- Equipment which cannot be provided by the NHS Small, practical equipment that cannot be funded by the NHS.

Financial Review

Community and individuals

205 Facebook Fundraisers were created, with **1,213** donations. In total, £22,876 was raised (£22,803.65 in 2020) Through JustGiving we raised **£47,854.59** (£22,799.91 was raised in 2020, but in 2020 we also raised £91,437.46 in 2020 from Virgin Money Giving, which closed its doors in early 2022). In total through digital fundraising (Facebook and JustGiving) we raised: **£70,730.59** (£137,041.02 in 2020)

Heart Month

Our Heart Month fundraising was greatly impacted by national lockdowns due to the COVID-19 pandemic. In total we raised **£1,100**.

Secret Santa

In total we raised **£2,067.18** (£2,727.50 in 2020) in our annual festive fundraiser, funding the provision of games, books and festive treats for children and young people in hospital over the festive period. £800.18 was donated via ECHO's website fundraiser. £1,267 donated via ECHO's Facebook Fundraiser.

Events:

In 2021, due to high cases of COVID-19 and national lockdowns ECHO's in-person events remained paused. ECHO's own Up & Over event was cancelled, for the second year.

We had individuals registered to compete in several fundraising events, which were cancelled: 5 runners in Brighton, 2 at London Marathon, 5 at Royal Parks Half Marathon. The Virtual London Marathon took place, where 7 individuals took part for ECHO. We also had 2 individuals who took part in the Ride Across Britain challenge event.

Grants and Trusts

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

- CAF Resilience Fund
- Card Factory
- Partners for Health Programme
- Children in Need
- True Colours Trust
- Shanly Foundation
- Charles S French Charitable Trust
- Garfield Weston
- The Mabel Harper Charitable Trust
- DCMS Pear
- The Hamilton Wallace Trust
- The Thales Charitable Trust
- The Thomas Sivewright Catto Charitable Settlement
- Children in Need 3rd instalment
- The Sir Jules Thorn Charitable Trust / Ann Rylands
- Souter Charitable Trust
- National Lottery Community Fund
- Chapman Charitable Trust
- Colyer-Fergusson Charitable Trust
- Albert Hunt

Organisations and individuals we wish to thank:

Ronald McDonald House Evelina

Through our partnership with Ronald McDonald House Evelina we have been able to source space for ECHO to provide wellbeing clinics to NHS nursing teams from the cardiology teams.

Box4Kids, run by Barrie Wells Trust, who help us to provide special days out and experiences to children and young people affected by heart conditions by providing executive box tickets.

Chris Harris, ECHO volunteer for kindly donating some beautiful books to ECHO to distribute to children visiting Evelina London for cardiac related appointments and treatments

We are little wild co'

10% of profits of their festive range have been donated to ECHO, raising £84.

Congenital and Children's Heart Forum

ECHO sits on the Congenital and Children's Heart Forum. A National and local congenital and children's heart Charities working together speaking collectively to forward the needs of patients and families living with heart disease, including: Little Hearts Matter, Tiny Tickers, Heartline, Children's Heart Federations, Max Appeal, Sommerville Foundation, Downs Heart Group.

KCL – Public Engagement Advisory Board

The Wellcome/EPSRC Centre for Medical Engineering PE Engagement Advisory Board at King's College London offers opportunities for ECHO's Chief Executive and team to input into the activities and opportunities within King's Wellcome/EPSRC Centre for Medical Engineering departments, grant panel experience for our fundraiser, introductions to community groups across Lambeth and Southwark & Partnership projects connecting researchers, scientist and the ECHO community.

Byron Gold

Thanks to Byron Gold & Choir for providing musical entertainment at a special event for cardiology staff, sponsored by ECHO.

Nikki Talbot – Studio HOIME

Thanks to Nikki for working with us to provide wreath-making kits to ECHO families at home, as part of our online Opening Doors event.

ECHO as Charity of the Year

ICCM (Institute of Cemetery and Crematorium Management)

Thank you to Kevin and Eddie from the ICCM (Institute of Cemetery and Crematorium Management) for choosing ECHO as their selected charity and raising £10,000. Assistant Chief Executives Directorate Eddie, his granddaughter Eliana and their family are ECHO members, and decided they wanted to give back to the ECHO heart community which has supported them.

Vengan Legal Services

This year ECHO has been selected as Charity of the Year by Vengan Legal Services who are donating 10% of any will writing fees to ECHO. Thank you.

Impact of our services: (2021)

During 2021, ECHO welcomed **127** new families to the ECHO heart community (**175 in 2020**)

Each family represents parents, carers, children with heart conditions, siblings and other family members so the number of individuals ECHO supports is much higher.

Connecting our community

Opening Doors

In November 2021, in response to COVID-19 restrictions, ECHO held the virtual event 'Opening Doors' on YouTube Live. The purpose of Opening Doors was to connect members with one another and with academic, medical and ECHO staff during a time of isolation. 11 medical and academic staff were interviewed as part of the event. In addition, an interactive wreath-making workshop was streamed which families took part in, 50 wreath-making kits were posted out on a first-come, first-served basis.

63 ECHO families watched live and ECHO's YouTube channel had **264 views** on the day of the event.

ECHO Happiness Hub

At ECHO we collaborated with scientists from the School of Biomedical Engineering & Imaging Sciences at King's College London to run 12 weeks of creative online ECHO Happiness Hub workshops. The livestreamed workshops were hosted by creative professionals, with several sessions featuring heart and brain researchers. The workshops aimed to provide families watching at home and in hospital a relaxing, distracting space to take part in a live creative workshop and connect with scientific researchers in a new way.

Huge thank you to everyone who helped put this event together. It has been extremely informative (even though we are nearly 13 years in to our journey) - it is great to hear about everything that goes on in the background that we are not aware of - ECHO member

Our offer to young people

To tackle the impact of COVID-19 on ECHO's ability to host in-person events for young people, we created an online film club for young people affected by heart conditions, aged 11-24 years.

40 young people signed up and we held online sessions every month led by a professional filmmaker together with the ECHO Youth Team. Each young person received a Film Club pack to their home

which included items to aid them in creating films from their smartphone, a clapperboard, ECHO Teens t-shirt, tote bag and notepad.

The result we hope in 2022 is to release a short film made by young people.

Supporting NHS staff

While cardiac staff continued their excellent work supporting families of children and young people affected by heart conditions, ECHO wanted to continue our support of the cardiac team.

We aided nursing teams to run 3 nurse wellbeing days, providing relaxation and catering as well as supporting team activities on the day.

We supported a team cardiology event, providing wellbeing terrariums for every member of team cardiology, we also provided live music with an emotional tribute to the work team cardiology has done over the pandemic.

Across 2021 we continued to award nominated recipients with ECHO Excellence Awards, these are unique to the cardiology department across the Evelina London, Royal Brompton Hospital and their networks and nominations arrived from parents/carers/patient & NUS colleagues to celebrate the difference that they make to cardiac families.

"It's such a honour to get this award, thank you very much." - ECHO Excellence awardee

"Thanks very much – you have made my day." - Dr Aaron Bell, Head of Paediatric Cardiology, Evelina London.

Diversity and representation

Our first project carried out with the newly joint Evelina London and Royal Brompton & Harefield – ECHO led on an inclusivity project, starting off at a photo shoot event held at Chislehurst Golf Club where families affected by children's heart conditions came forward to represent their community and lives.

We were delighted to meet with more people than we expected, and had the support from the Evelina London CHD Network Manager, the adult nursing team and ECHO volunteers. The result was a new catalogue of images which will be used by ECHO and Evelina London across communications.

80 ECHO members attended the photoshoot, including 26 groups/families and 4 volunteers.

Support in hospital

ECHO continued our in-hospital support and reviewed ways we could expand our services while in-hospital volunteering remained paused within Guy's and St Thomas' Trust. We sent our annual Mother's Day and Father's Day packs to parents in hospital – **50** of each of these packs were delivered to Evelina London's Sky ward and PICU.

We launched our new ECHO Cares pack – a welcome bag with information for parents arriving in hospital about how ECHO can help, key hospital contacts, an eye mask, notepad & pen and Eddie ECHO teddy. We sent **100** ECHO Cares packs to hospital every 3 months.

In Summer 2021 we began work on a new resource, aimed at children with heart conditions and their siblings in hospital. The resource seeks to provide distraction and fun to children while undergoing treatment and recovery or spending time in hospital while a sibling undergoes treatment. The resource will launch in 2022.

In addition to the above, ECHO sent arts and crafts into hospital for families during the festive period and at request of the Paediatric Cardiology Play Team.

Listening to our members

In 2021 we carried out a member-wide survey, with the aid of King's College London Msc Health Psychology Placement Programme student. The questionnaire focused on finding out about our community's experience of engaging with ECHO and how

What are the most beneficial ways ECHO supports heart families? The top three answers were:

- Providing useful information to families when needed (eg website)
- Providing answers to the questions from families, or helping them get questions answered by someone else
- Connecting heart families with others in a similar situation

Where would you look if you are searching for information about your child's treatment or care?

The top three answers were:

- Evelina London website
- ECHO website
- ECHO Facebook group

Volunteer contribution

Volunteers continued to make an impact to ECHO in 2021, despite our in-person volunteering opportunities needing to remain paused due to the impact of COVID-19.

Our group of dedicated antenatal volunteers have continued to support families whose unborn baby has been diagnosed with a heart condition, by joining the online version of ECHO's cardiac antenatal class. We would like to thank our volunteers Amanda, Ben, Chloe, Claire, Elissa and Marion for giving their time and for their ongoing support.

2 volunteers supported ECHO remotely with communications projects, such as adding content to the ECHO website, reviewing and sharing ECHO parent and carer stories and creating content for ECHO's social media channels.

2 volunteers gave their time to take part in the CHD Network's Hospital Scoping Project, whereby ECHO connected with hospitals across the Evelina Guy's & St Thomas' Network to gather information about their patient and user involvement, specific cardiac volunteering opportunities and parent involvement.

ECHO sits on the CHD Network Board and this project has greatly assisted the CHD Network team in their development of the network. **1** ECHO volunteer kindly took on the role of managing the online ECHO shop from their home, packaging and posting items purchased on the ECHO website including Eddie ECHO teddies, pens and t-shirts.

We'd like to thank everyone who gave their time and skills during the year to help us to continue to deliver our services. We look forward to resuming in-person opportunities and seeing you soon.

Plans for future

Looking ahead for 2022 we plan to:

- Develop our services - including a new online ECHO Forum
- Extend our young people's service to support from 0-18 to 0-25 years of age
- Develop and expand our staff team
- Review our website, language and communications to be more inclusive of congenital and acquired conditions
- Prepare to reinstate our volunteer service
- Plan to celebrate and increase fundraising activity over our 40th birthday in 2023

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. In 2019, we worked with Tom Searle of Britrisk Safety

Limited to run risk assessment training to ECHO staff and reviewed our Health and Safety & organisation's Risk Policy.

Declaration

The trustee directors declare that they have approved the trustee directors' report above. Signed on behalf of the charity's trustee directors:

Jane Ward

EVELINA CHILDREN'S HEART ORGANISATION
(A company limited by guarantee)

Registered Charity number 1146494

Company Number 7867592

ACCOUNTS FOR THE PERIOD FROM 1 JANUARY 2021 TO 31 DECEMBER 2021

Evelina Children's Heart Organisation Limited
Accounts for the period from 1 January 2021 to 31 December 2021

Charity Name	Evelina Children's Heart Organisation Limited
Working Name	ECHO
Charity Number	1146494
Company Number	7867592
Registered Office	Canterbury House, 1 Royal Street, London. SE1 7LL
Board of Trustee Directors	James Pincus Patricia Jane Ward Joanna Eyeson Alex Bicknell Stephen Wood Marc Harry
Independent Accountant	Danestone Business Services Ltd 52 Crown Drive, Inverness. IV2 3QG
Bank	CAF Bank 25 Kings Hill Avenue, Kings Hill, West Malling, Kent, ME19 4JQ

Evelina Children's Heart Organisation Limited
Notes to the Accounts

Note 1: Accounting Policies

The principal accounting policies are summarised below. The accounting policies have been applied consistently throughout the period.

Basis of Accounting

The financial statements have been prepared on the basis of the historic cost convention and in accordance with the Companies Act 2006 and the Statement of Recommended Practice - Accounting and Reporting by Charities (SORP 2005) issued in March 2005.

Fund Accounting

Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity. Restricted funds are subjected to restrictions on their expenditure imposed by the donor.

Incoming resources

All incoming resources are recognised once the charity has entitlement to the resources, it is certain that the resources will be received and the monetary value of incoming resources can be measured with sufficient reliability.

Grants and donations are included in the SoFA when the charity has unconditional entitlement to the resources and incoming resources from tax reclaims are included at the same time as the gift to which they relate.

Investment income is included when receivable.

Resources expended

Expenditure is recognised on an accrual basis as a liability is incurred.

Costs of generating funds are those costs incurred in attracting voluntary income.

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its members. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature to support them.

Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include independent examination fees and costs linked to the strategic management of the charity.

All costs are allocated between the expenditure categories of the SoFA on a basis designed to reflect the use of the resource. Costs relating to a particular activity are directly allocated.

Fixed assets

Tangible fixed assets are stated at cost less depreciation. Depreciation is provided at rates calculated to write off the cost useful life as follows:-

Computer equipment - 33.33% straight line basis

Evelina Children's Heart Organisation Limited
Statement of Financial Activities
For the period from 1 January 2021 to 31 December 2021

	Unrestricted Funds Period Ended 31 December 2021 £	Restricted Funds Period Ended 31 December 2021 £	TOTAL FUNDS Period Ended 31 December 2021 £	TOTAL FUNDS Period Ended 31 December 2020 £
Incoming Resources (Note 3)				
Donations	164,268	125,847	290,115	378,878
Investment Income	42	0	42	138
Job Retention Grant & SSP	58	0	58	3,347
Total Incoming resources	<u>164,368</u>	<u>125,847</u>	<u>290,215</u>	<u>382,363</u>
Costs of Providing Charitable Activities (Note 4)				
Cost of fundraising	44,021	0	44,021	40,864
Charitable Activities	51,960	121,679	173,639	135,276
Governance	763	0	763	750
Total Resources expended	<u>96,744</u>	<u>121,679</u>	<u>218,423</u>	<u>176,890</u>
Net movement in funds	<u>67,624</u>	<u>4,168</u>	<u>71,792</u>	<u>205,473</u>
Reconciliation of funds				
Total Funds brought forward	<u>233,299</u>	<u>6,832</u>	240,131	<u>34,658</u>
Total Funds carried forward	<u>300,923</u>	<u>11,000</u>	<u>311,923</u>	<u>240,131</u>

Evelina Children's Heart Organisation Limited
Balance Sheet as at 31 December 2021

		31 December 2021	31 December 2020
		£	£
Fixed Assets	(Note 5)	785	0
Current Assets			
Debtors/Prepayments	(Note 6)	13	6,978
Cash at bank and in hand		319,218	238,757
Total Current assets		<u>320,016</u>	<u>245,735</u>
Creditors falling due within one year	(Note 7)	(8,093)	(5,604)
Net Assets		<u>311,923</u>	<u>240,131</u>
Funds of the Charity			
Unrestricted Funds		300,923	233,299
Restricted Funds	(Note 8)	11,000	6,832
Total Funds		<u>311,923</u>	<u>240,131</u>

For the year ending 31 December 2021 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

* The members have not required the company to obtain an audit of its accounts for the year in question in accordance with section 476

* The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts.

These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime

Chair *STEPHEN WOOD*
JfWood
 Date: *2/9/2022*

Note 2: Trustees Remuneration

No remuneration was paid to the trustees in the 12 month period ended 31 December 2021.
No expenses were paid during the period.

Note 3: Analysis of incoming resources

**Total Funds
12 month period to
31 December 2021**

£

Voluntary income:

Unrestricted donations

164,268

Restricted donations

125,847

Gift Aid

0

Government JRS

58

Investment income:

Bank Interest

42

Total

290,215

**12 month period to
31 December 2021**

£

**Note 4: Analysis of
charitable activities**

Back Office/Admin

34,030

Volunteers

225

Information

8,307

Member Support

131,077

Total

173,639

Note 5: Fixed Assets

	Computer Equipment £
<u>Cost</u>	
At 1 Jan 2021	2,838
additions	1,179
<u>At 31 Dec 2021</u>	<u>4,017</u>
<u>Depreciation</u>	
At 1 Jan 2021	2,838
additions	394
<u>At 31 Dec 2021</u>	<u>3,232</u>
<u>Net Book Value</u>	
At 1 Jan 2021	0
At 31 Dec 2021	<u>785</u>

Note 6: Analysis of Debtors/Prepayments

	£
Prepayment :2022 Confirmation statement	<u>13</u>

Note 7 : Analysis of Creditors

	£
<u>Accruals</u>	
Trade creditors	4,753
PAYE, NIC, Pension	3,340
	<u>8,093</u>

Note 8 : Ringfenced Income

Balance B/F	6,832
Ringfenced Donations	125,847
Expenditure	(121,679)
Balance C/F	<u>11,000</u>



Section A

Independent Examiner's Report

**Report to the trustees/
members of**

Charity Name
EVELINA CHILDREN'S HEART ORGANISATION LIMITED

**On accounts for the year
ended**

31 DECEMBER 2021	Charity no (if any)	1145494
------------------	--------------------------------	---------

Set out on pages

1-7

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31/12/2021.

**Responsibilities and
basis of report**

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

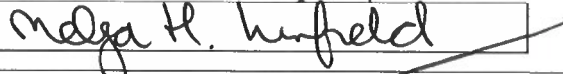
**Independent
examiner's statement**

The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of The Institute of Chartered Accountants in England and Wales.

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed: 

Date: 28 AUGUST 2022

Name: MELZA HELEN LINFIELD FCA

**Relevant professional
qualification(s) or body
(if any):**

ICAEW

Address:

DANESTONE BUSINESS SERVICES LIMITED

52 CROWN DRIVE

INVERNESS, IV2 3QG

Section B

Disclosure

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

[Empty box for disclosure details]

EVELINA CHILDREN'S HEART ORGANISATION LIMITED

England & Wales - Charity number 1146494

Accounts



EVELINA CHILDREN'S HEART ORGANISATION LIMITED

(A Company Limited by Guarantee)

Registered Charity Number: 1146494

Company Number: 7867592

REPORT OF THE BOARD OF TRUSTEE DIRECTORS

FOR THE PERIOD 1 JANUARY 2020 TO 31 DECEMBER 2020

Evelina Children’s Heart Organisation Limited

(A company limited by guarantee)

Report of the Board of Trustee Directors for the Period 1 January 2020 to 31 December 2020

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: Jane Ward

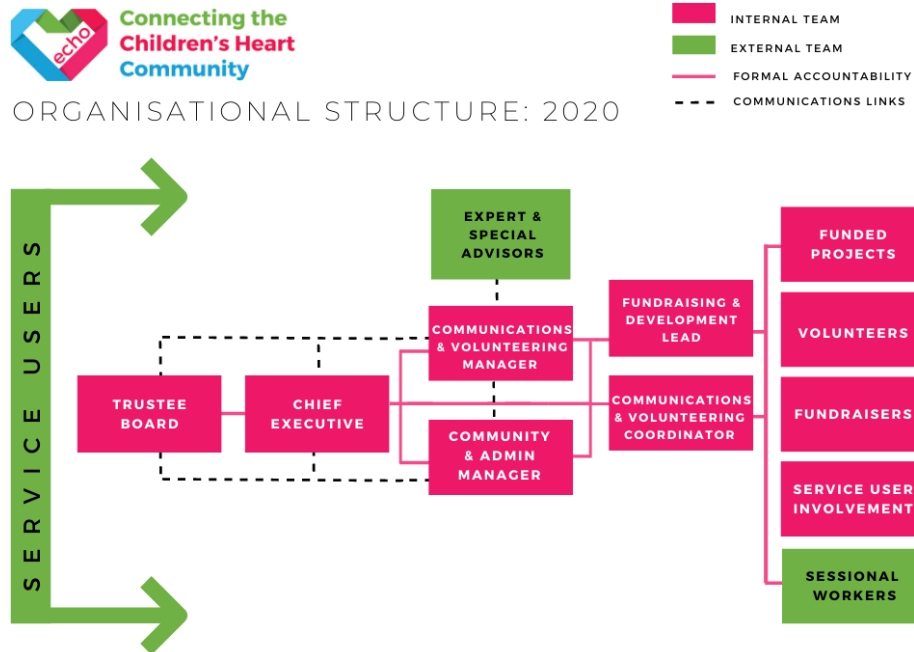
Trustees:

- James Pincus
- Patricia Jane Ward
- Alex Bicknell
- Joanna Eyeson
- Stephen Wood
- Marc Harry

Staff:

- Chief Executive, **Samantha Johnson**
- Community & Administration Manager, **Emma Orpin**
- Communications & Volunteering Manager, **Siobhan Morton**
- Communications & Volunteering Coordinator, **Sinéad Houlihan**
- Fundraising & Development Lead, **Kate Smith**

ECHO organisational structure – 2020



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

Our mission, vision and values:

- Mission: to support children affected by heart disease & treated by the Evelina London Children's Hospital networks, and their families.
- Vision: a world where the emotional, social, financial and medical needs of heart families are met.
- Values: Resilient, Empowering, Supportive, Open & Honest, Resourceful, Impactful

About ECHO:

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. 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 we support:

- Children and Young People with heart conditions from birth to 19
- Parents/Carers diagnosed either prenatally or during childhood throughout their child's life, at times when they need us
- Siblings of those affected with CHD from birth to 19 living with a heart child
- Wider family who support echo members
- Professionals surrounding families at the Evelina London and networks

How ECHO supports heart families:

- Information & Guidance: ECHO provides information and advice via our website, leaflets, social media, newsletters, DVDs and books for children.
- Antenatal classes: ECHO funds bespoke cardiac antenatal classes for parents whose unborn child has been diagnosed with a heart condition.
- Parent/Patient advocacy: ECHO represents patients and parents locally and nationally to improve patient/carer experience, campaign for improvements to government benefits as well as act as an objective partner for families with queries regarding their child's care.
- Hospital Resources: New spaces in hospital: redesigning & revitalising spaces within Evelina London including the parent's room and new psychology space
- Discharge & Pregnancy packs: specialist information packs.
- Comfort packs: Packs for parents whose children have arrived at hospital in an emergency, containing practical help at a time when nothing else is available.
- Gift packages on Mother's and Father's Day
- Events: Events for heart children, their parents and siblings, helping to reduce isolation, promote wellbeing, improve local support networks and enable families to meet others who are experiencing a similar situation.
- Parent-to-Parent Support: ECHO organises & trains volunteers who provide emotional support at hospital, on the telephone, via email or through organising & participating in local events.
- Online forum: ECHO manages a closed Facebook group enabling heart parents to meet online and share stories.

- Support for Dads: Documentary film offering advice and reassurance to fathers and male carers of a child with a heart condition.
- Support for Siblings: Annual ECHO Sibling Day gathering, plus information and guidance designed specifically for siblings.
- ECHO Teens: information & guidance, fun activities and helping young people transition to adult hospital services.
- Bereavement Support: Remembrance gatherings and small bereavement grants.
- Toys & Crafts: Toys and crafts for children at Evelina London Children's Hospital.
- Equipment which cannot be provided by the NHS Small, practical equipment that cannot be funded by the NHS

COVID-19 Crisis & ECHO's Response

2020 has been a challenging year for everyone and ECHO has been no exception. During the pandemic, we have made a priority of listening to the heart community including parents, carers, patients, professionals and supporters.

We initially focused on **keeping our community safe**, closing the office and ensuring all staff were able to work from home, and also withdrawing all ECHO face to face volunteers from frontline services. This was a challenge for ECHO as we required additional laptops, chairs and resources that we had previously not needed or implemented.

We saw our income from community events and individual donations dropping. Traditional income streams dried up overnight and we had no choice but to utilise the government **furlough** scheme and **COVID-19 emergency appeals**. We launched an emergency fundraising appeal, letting our community know the very real problems faced by ECHO due to the pandemic.

"Smaller charities, in particular, are at risk of imminent closure if adequate support is not provided"
 – UK Government.

ECHO's services:

- During 2020, ECHO welcomed **175** new families to the ECHO heart community – we also welcomed families who were previously treated at the Royal Brompton and Harefield Hospitals.

“When we didn’t get a shielding letter I had no idea where to turn, my GP told me to be patient but my child’s life was at risk...ECHO was able to reassure me and get the information I needed to make decisions, it turns out my child did need to isolate and we were able to keep them safe at home”

- We launched a dedicated **COVID-19 web page** and provided direct support to families by email, phone and via our online community group as well as hosting online sessions for parents to connect with others and with the ECHO team. **The ECHO team pulled together to support more people than we ever have - an increase of 1600% over the first 6 months of the pandemic.**

“ECHO helped us during the pandemic with keeping us up to date on recommendations for children with heart conditions.” - ECHO member

- We launched the **ECHO Cares packs** to support cardiac families in hospital, sending **150** packs every 3 months. Through the ECHO Cares pack, we are ensuring that we reduce isolation for families in hospital by welcoming them to ECHO with a beautiful cotton bag, packed with a comfy eye mask, cuddly ECHO teddy bear, hand sanitiser, notepad and pen plus information on support available from ECHO, useful hospital contacts list, and a postcard to send love from hospital, to those at home who have been unable to be with them due to COVID-19 hospital visitor restrictions.

“Knowing my son needed open heart surgery and I wouldn’t be at his side was traumatic, I wanted to support my wife and hold my sons hand but couldn’t. I spent 7 days outside the hospital hoping not to get a call that my son didn’t make it - instead I spoke to ECHO and they helped my find a place to stay when I thought the world was closed - thank you ECHO”

- In 2020, ECHO funded, designed and opened a new **Cardiac Psychology and Play Space:** [‘The Lodge’](#), at Evelina London.



'The Lodge', a new cardiac psychology room funded by ECHO opened earlier this year has been a very safe, quiet place for psychology sessions to happen when I have met families in hospital. It has really helped to have a separate, dedicated room especially for young people to access, away from the ward, to talk through how they are feeling. I'd like to thank everyone who donated to ECHO and made this room possible. - Niki Gregg, Clinical Psychologist

- We moved our popular **ECHO Cardiac Antenatal Classes online** and launched [new resources](#), with information for newly diagnosed heart parents about their care and delivery, guidance about the Neonatal Intensive Care Unit, messages and stories from other heart parents, and suggestions of how to prepare for their hospital stay.

"I found the ECHO antenatal classes I attended by zoom amazing. I was able to meet other parents facing similar situations and I connected with another mum who was expecting a little boy with the same condition as my baby. We have remained friends and supported each other through this challenging time." - ECHO member

- We launched the [ECHO Happiness Hub](#), where we have shared fun, inspiring and uplifting activities for families to take part in during lockdown including a video from our patron Mister Maker and videos from scientists at King's College London.

"I have been living as a single parent for eight months, my husband moved out to keep my daughter safe and just sees us through the window, ECHO called to check in with me and had some fun activities online that really helped me". - ECHO member

ECHO & Evelina London/Guy's and St Thomas Hospital Trust

- Throughout the year, we kept our community up to date with the latest information relating to [COVID-19](#), holding **weekly meetings with Evelina London's senior cardiac team** vs our usual monthly meetings, to address parent concerns and keep in the loop with hospital changes.
- We directed non-medical calls away from the hospital to ECHO over covid-19 via specialist nurses **answerphones**.
- We began plans for a Clinical Nurse Educator/ECHO **programme of wellness activities** for Nurses & Introduction to ECHO

- With input from cardiac teams, we **shared the latest government, NHS and British Congenital Cardiac Association advice** on our dedicated Coronavirus web page, social media, and our e-newsletter.
- We sent goodie bags and **180 afternoon teas** into hospital, encouraging staff, patients and parents to take five minutes to reflect over the year as part of our Virtual Together for Tea' initiative.



- On **Mother's Day and Father's Day**, ECHO sent **100** gift packs for parents staying in hospital at Evelina London. Each pack was put together by volunteers and filled with sweet treats, personal hygiene items and reusable coffee mugs plus a reminder of how parents can reach out to ECHO for information or to connect.

"We are going through so much when we are in the cardiology ward with our babies... Thank you is not enough for everything you guys do to make our day lighter" - ECHO member

- ECHO supported the new **Sky ward** by consulting with parents to design the new space. We love the light & airy design with more access to nursing desks. We championed a new 'quiet space' away from the hustle and bustle of the ward, as well as a dedicated parent's space and breastfeeding room.
- In response to the incredible dedication and hard work of cardiac teams across the Evelina London, Royal Brompton and their network hospitals, together with the Evelina London cardiac team ECHO made plans in mid-2020 to launch the '**ECHO Excellence Awards**' in 2021, celebrating all the wonderful cardiac NHS staff who treat and care for the children in our community.

- In 2020, ECHO started a **network hospital project** with the Evelina London Congenital Heart Disease Network to improve cardiac patient experience. ECHO supported the development of a network scoping project to connect and gather information from each Evelina London network hospital – the project began in early 2021 and will be carried out by dedicated ECHO **volunteers**.
- ECHO supported one of our members Emma who came up with a brilliant idea to create a **banner** full of photos of ECHO families to say thank you to Evelina London Cardiology team. ECHO families joined together by sharing photos of their heart heroes for a large banner display in front of the ECHO office, opposite the hospital. We know how hard all staff are working right now and we hope this is a cheerful reminder about how much the ECHO community values their support and care. Staff and families have been stopping by for a photo when they are nearby.



Media & Communications

Website

We spoke to medical experts on the frontline tackling COVID-19, produced letters for schools and employers, created a [webpage](#) for COVID-19 information and worked hard to reassure or seek guidance for our community.

In the **first 6 months of the pandemic**, the ECHO website was visited **10,000 more times** than the same period in the previous year.

Festive Fortnight

On social media, together with the Evelina Cardiology team, we published a daily 'Festive Calendar' for 2 weeks over the festive holidays full of photos, videos and messages from members of the ECHO heart community including cardiac staff, ECHO fundraisers, volunteers, partner organisations and families to celebrate community achievements and share positive messages during a time when we could not be together.



Fundraising & Events

Heart Month Party

Pre COVID-19 in **February**, ECHO held the annual Heart Month party at the Evelina London. **7** ECHO volunteers helped run the day and make it fun for children and parents in hospital, including running an ECHO leaflet/information table, LEGO activity table, arts and crafts, refreshments and a photo booth. We also provided Heart Month decorations for the hospital's parent rooms.



Bloom & Grow community workshop

Also in **February**, pre-COVID-19, ECHO held a new event - **Bloom & Grow Flower Workshop** - a paid session for families to come along for a hands-on flower workshop in aid of ECHO, while connecting with others.



Cancelled events

Since national lockdown rules were established in **March** in response to COVID-19, social distancing made delivering services harder and more costly. This, together with the vulnerability of the children and families we serve, meant we had to take the painful decision to postpone or cancel all face-to-face activities and events throughout 2020.

We saw our income from community events and individual donations dropping. Traditional income streams dried up overnight and we had no choice but to utilise the government furlough scheme and COVID-19 emergency appeals. **Throughout 2020**, whilst we increased income from emergency COVID-19 appeals and trusts and foundations, **we lost over £96,000 from individual events and fundraising.**

ECHO arranged our first **science night sleepover at the Science Museum** on 7th March - this was cancelled due to COVID-19 - but we had **19 young people** signed up to attend as well as **8** medical volunteers.

ECHO supporters and organisations including in the hospitality sector had events planned in their workplaces, communities restaurants. This included an evening dinner event and members coordinating with their workplace to encourage fundraising in their office. Unfortunately, due to COVID-19 restrictions offices, restaurants and other hospitality companies were forced to close,

meanwhile fundraising for ECHO could no longer go ahead. As offices and restaurants, cafes and shops reopen and many employees return to working in the office at least some of their working week, we look forward to these fundraising opportunities resuming.

Online events

Breakfast with ECHO & alpacas

In response to families facing isolation due to shielding, distancing and hospital COVID-19 restrictions, we wanted to give families a space online to take a break and do something fun and relaxing while from home. Children and families met our **special alpaca guests in a morning livestream from their farm in Kent** – getting to see them close up (virtually!), ask questions about their lifestyle and win prizes like a cuddly alpaca toy.

We received feedback from parents that their children hugely enjoyed these sessions both while in hospital and at home, and families looked forward to joining each session.

Virtual games night

*In July, ECHO supporter Gary and the BNI Keane network held an online **Spectacular Gameshow Mashup**, inviting people to donate and enjoy a night of online games as we all navigated a world without face to face fundraising events.*

“We have heard first-hand about the wonderful work that ECHO does through regular meetings with Charity Chief Executive Sam. The support families receive from ECHO is invaluable. We want to help support more families in their times of need.”

1 in 100 campaign

In summer 2020, **77** ECHO members from across the country, all supported by ECHO and treated by the Evelina London Cardiac Team, are featured in a parent-created #1in100 music video appeal to raise awareness and vital funding to help other children with heart conditions.

Families shared their personal experience of Congenital Heart Disease in order to support new families receiving a diagnosis and showing the public the story behind the journey. The 77 children featured in the appeal video *I Am Home*, sung by Byron and the Stratford East Singers,

were connected by Evelina Cardiology Mum Caroline. Together, the families raised over **£10,000** as well as promoted awareness of CHD and the journey families take.



2.6 Challenge

Families and supporters took part in the national 2.6 Challenge, a response to the charity sector's struggle after events were cancelled. **ECHO supporters ran, cycled, baked and even played chess!**

Secret Santa appeal

In December we would normally visit the hospital to drop off gifts and invite our volunteer Elves to meet children staying in the hospital. Instead we focused our **Secret Santa appeal** on bringing fun and play to children in hospital by providing **arts and craft packs** for children and young people and festive treats for parents and staff supporting them in hospital.

Through Facebook and a website appeal, we raised **£2,495** which we used to provide play workers with the arts and craft packs to run 1:1 arty sessions with heart children at the bedside. These



sessions give children a much-needed distraction from their treatment and recovery, and help them to express their thoughts in a safe and creative space with a dedicated specialist.

Yeo Valley Award

ECHO was nominated by a member of our community for the Yeo Valley Award, and we were selected as one of their 'charities of the quarter' in Winter 2020. We provided a blurb and photo and were featured on the Yeo Valley website, which meant shoppers purchasing Yeo Valley products could give their 'yeokens' to a charity of their choice. The charity which received the most 'yeokens' would receive a **£1,500 prize** and we were delighted that ECHO received the most yeokens. This award is with a big thanks to our community of families and supporters who think of us when coming across charity projects like this one.

ECHO Team

Our small part-time team also faced the same concerns over COVID-19 as everyone else, impacting on what we were able to do and when. The team pulled together to work out of their "normal hours", balancing working from home, home schooling and the increased needs of members and ECHO's services to ensure our vital work could continue.

ECHO's board meetings changed from quarterly to monthly virtual meetings, in order to support the CEO in strategic thinking and decision making.

Like many charities we are fighting for survival and we are unsure of where our income for the next year or two will come from. However, for the moment we can be proud of what we achieved throughout 2020, especially in the dedication of the small team, volunteers, board and professionals we work with - **without these strong relationships we simply wouldn't be here.**

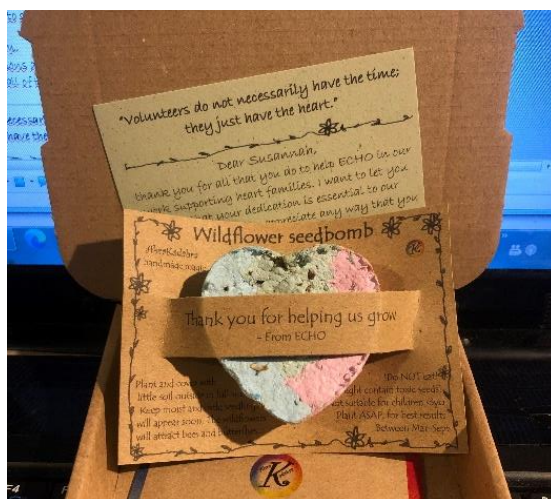
Volunteers

72 volunteers helped achieve our mission pre-COVID-19; they supported us in the office, provided admin help to community fundraisers, visited parents in the hospital, ran support groups, dressed as Christmas Elves, and created the fun and friendship at our activities and events - we miss you all and hope to see you in the future once things are safe.

In light of the national lockdown all face to face volunteering services were paused, this included antenatal volunteers, ward visits, office, admin and communications volunteering roles.

ECHO's **communications volunteer** remained in the role throughout the summer, working remotely to support writing social media posts, design content and family stories for the website.

At the end of 2020, ECHO volunteers each received a **gift and note** from us with a reminder of how much we appreciate them, despite not being able to be together this year. The gift was a heart shaped 'seed bomb', which once planted grows into wildflowers.



ECHO member story

Tracy's story:

"We found out about Isabella's diagnosis from the 20-week scan and a later scan diagnosed VSD. On hearing Isabella may need surgery soon after birth, we were shocked but on hearing the words open heart surgery, it felt even scarier. Despite COVID-19, apart from a delay to the fetal MRI we have been lucky with all appointments going ahead as planned. We went to the main diagnosis scan appointments together but all follow up scans I went by myself, due to hospital COVID-19 restrictions, which was hard for us both.

I first joined ECHO and the ECHO Facebook group following advice from the cardiac nurse. It was really helpful, from seeing that you're not alone in your situation to advice from other's experiences. I joined the ECHO antenatal class which was being run on Zoom instead of at St Thomas' Hospital – it was strange at first but was really good and the information was helpful. We were on the cardiac ward with another couple from the class, so that was nice to be able to see their progress and a friendly face. **In these strange times it was a comforting way of making the best of the situation.**



I was due for a planned induction but our little one arrived a few days early. Throughout our time in the hospital, being able to have only one of us with Isabella at a time was really difficult, especially for support, although all of the staff were wonderful. We have been lucky so far and Isabella hasn't had to have any surgery. We're loving the addition to our family; her personality is growing and she's becoming more alert with the biggest beautiful smile and we couldn't love her more."

Financial Review

Our total income in 2020 was **£382,363**

- Our total from Facebook Fundraising was **£22,803.65**
- Our total from online fundraising platforms was **£22,799.91** from JustGiving and **£91,437.46** from Virgin Money Giving
- Together on Facebook, Virgin Money Giving and JustGiving our income was: **£137,041.02**

Trusts & Foundations

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

- Guy's & St Thomas' Charity
- Children In Need – Emergency COVID-19 'Booster' Fund
- Southwark Council
- Colyer Fergusson Charitable Trust
- Whitehead Monckton
- Lottery Community Fund
- Kent Community Resilliance Grants
- St James Place Foundation
- Albert Hunt Trust
- Edith Florence Spencer Memorial Trust
- Helen Robertson Trust
- Lennox Hannay Charitable Trust

Relationships

King's Health Partners Cardiovascular and Respiratory Partnership - Patient-Public Reference Group:

- NHS England's children's heart and lung services consultation
- Representing patients/parents
- Meeting parents and patients from across specialties and hospitals
- What could the future London Landscape be for children's and adults heart surgery
- Meeting the congenital heart disease standards
- Tour of the Royal Brompton Hospital

King's College London, Centre for Medical Engineering and EPSRC Centre:

For the past three years, ECHO has been collaborating on projects led by [Cellule Studio](#) and Dr Pablo Lamata and his group from the department of [Biomedical Engineering](#) at King's College London (developing new technologies to treat heart conditions) exploring the future of medical imaging – such as computer simulations to help surgeons plan surgery.

Stay at Home with Scientists

“Throughout the summer, our researchers had fun creating short videos about their work for the ‘Stay at Home with Scientists’ series shared on ECHO’s social media, which aim to inspire the next generation of scientists. We are also currently creating some other exciting projects with ECHO - including fun science games and cartoons for ECHO’s new magazine for children visiting Evelina London, as well as some relaxing and engaging online workshops for parents too.” - King’s College London

‘Echoes’ heartbeat app

In **summer 2020**, ECHO supported the King’s College London team by **recruiting parents and young people to take part in online feedback sessions** on their new digital project, an app. Using the app, you can place your phone on your chest and hear and visualise the beauty of your heartbeat, or your loved ones heartbeats. At ECHO we are grateful to all of our members who kindly gave their time and experience to take part in workshops prior to the app’s launch to talk about their ideas and give feedback to the researchers and developers to help them shape the app.

Kings College London, Health Psychology Masters Placement Programme:

In January 2020, ECHO hosted a student from King’s College London for our second annual Health Psychology placement – the student supported ECHO by carrying out interviews and in-depth research into the **impact of the ECHO cardiac antenatal class on parents who attended**.

From March – May 2020 the placement was carried out remotely, with online supervisions and meetings taking place and the student produced a full report on her findings.

“I hadn’t really enjoyed my pregnancy and I was very worried and kind of came out [of the ECHO Cardiac Antenatal Class] feeling a bit more relaxed” - ECHO parent

House Committee – Evelina Ronald McDonald House:

- Regular communication around the COVID-19 restrictions and the impact on parents/carers and siblings
- Discussions with the accommodation coordinator for RMH & Evelina London

Patient Parent Voice – Evelina CHD Network:

- Attending CHD Network meeting- reps from local hospitals
- Reach out to the network hospitals thorough development of newsletter
- Supporting more cardiac families in the community

BNI Networking:

- Raising awareness of children’s heart disease and the journey families make to central London Hospitals from the home counties and further
- Recruiting volunteers to help with the CHD network scoping work
- Building relationships with business owners
- Raising money through charity of the year connections, individual direct debits and individual givers

CHD Charity Network Meeting:

- *ECHO, Little Hearts Matter, Heartline, Sommerville Foundation, Tiny Tickers , Children’s Heart Federation & Max appeal*
- Regular opportunities to discuss national and local services and issues facing the heart community from pre-natal to adulthood.

CHARLOTTE, ECHO ambassador

ECHO ambassador Charlotte has made a big impact in her first year supporting ECHO – after she released her stunning single “All My Life”, which she wrote when her nephew Archie was diagnosed with Congenital Heart Disease (CHD) and required heart surgery at just 6 days old.

In **October 2020**, Charlotte, family and friends including X-factor finalist Calum Scott (pictured here) climbed the Yorkshire Three Peaks for ECHO in a grueling 24 mile climb in tumultuous weather, raising almost £13,000 for ECHO heart families.

“Becoming an ECHO Ambassador has been a really special way for me to feel closer to my nephew, Archie. It’s a shame that this pandemic has made it more difficult to fundraise and to connect with the community in person. However, I’m really glad I got to complete one fundraising event and look forward to doing much more and meeting many more of you next year!”

Southbank University

With ECHO's support, the university has worked with parents and heart siblings to explore their experiences and build our 'heArt sibLings imPact Study' (ALPS), as there is generally not much information about how having a heart child in the family affects siblings.

"Thank you to ECHO for spreading the word, all the incredible families who have already been in touch and the amazing siblings I have been talking to these last few months. I am very privileged to learn more about this topic and hope to be able to improve support for siblings in the future based on our findings." - Lizzie Bichard, SBU

Looking forward to 2021

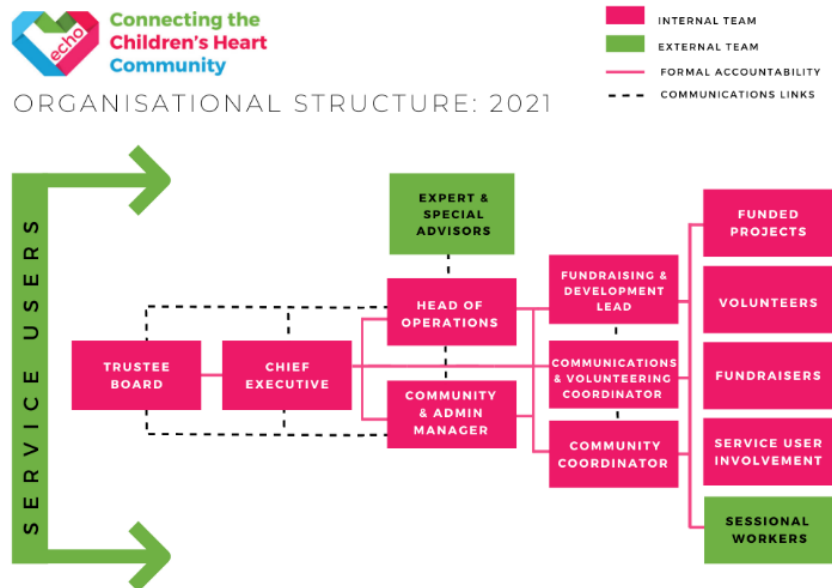
- We are excited to launch a monthly **ECHO Teens Film Club** in 2021 - for young people aged 11-17 with a heart condition and their siblings. Young people will be able to learn filmmaking skills from professionals, have fun and connect with other young people.

We look forward to welcoming ECHO Teen volunteer Karan to the virtual ECHO Teens Film Club when it launches in early 2021:

"I miss the face-to-face interactions when volunteering with our ECHO Teens group, drawing upon my own personal experience with CHD in order to mentor young people, siblings and parents on how to cope living with such a complex condition. I miss sharing my story on transition days and working with the lovely staff members in the office. Although there is no substitute for human contact, I relish the challenge that the new environment presents and look forward to supporting our ECHO Teens in a virtual setting!" - Karan, ECHO Teen Volunteer

- We look forward to launching **activity booklets** for children who are staying in hospital. These booklets aim to provide distraction and relaxation while they undergo treatment and recovery, and will be project-led by a young person with a heart condition with input from the cardiac teams and scientists.
- In 2021 we also look forward to creating our strategy and planning for a new ECHO forum – a way of connecting parents. Part of this project will be the recruitment of a dedicated **Community Coordinator**.

ECHO organisational structure – 2021



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 (this has been more frequent during the COVID-19 pandemic) 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. In 2019, we worked with Tom Searle of Britrisk Safety Limited to run risk assessment training to ECHO staff and reviewed our Health and Safety & organisation's Risk Policy.

Declaration

The trustee directors declare that they have approved the trustee directors' report above. Signed on behalf of the charity's trustee directors:

Jane Ward

EVELINA CHILDREN'S HEART ORGANISATION
(A company limited by guarantee)

Registered Charity number 1146494

Company Number 7867592

ACCOUNTS FOR THE PERIOD FROM 1 JANUARY 2020 TO 31 DECEMBER 2020

Evelina Children's Heart Organisation Limited
Accounts for the period from 1 January 2020 to 31 December 2020

Charity Name	Evelina Children's Heart Organisation Limited
Working Name	ECHO
Charity Number	1146494
Company Number	7867592
Registered Office	Canterbury House, 1 Royal Street, London. SE1 7LL
Board of Trustee Directors	James Pincus Patricia Jane Ward Joanna Eyeson Alex Bicknell Stephen Wood Marc Harry
Independent Accountant	Danestone Business Services Ltd 52 Crown Drive, Inverness. IV2 3QG
Bank	CAF Bank 25 Kings Hill Avenue, Kings Hill, West Malling, Kent, ME19 4JQ

Evelina Children's Heart Organisation Limited
Statement of Financial Activities
For the period from 1 January 2020 to 31 December 2020

	Unrestricted Funds Period Ended 31 December 2020 £	Restricted Funds Period Ended 31 December 2020 £	TOTAL FUNDS Period Ended 31 December 2020 £	TOTAL FUNDS Period Ended 31 December 2019 £
Incoming Resources				
	(Note 3)			
Donations	325,778	53,100	378,878	204,575
Gift Aid	0		0	623
Investment Income	138		138	115
Job Retention Grant & SSP	3,347		3,347	0
Total incoming resources	<u>329,263</u>	<u>53,100</u>	<u>382,363</u>	<u>205,313</u>
Costs of Providing Charitable Activities				
	(Note 4)			
Cost of fundraising	40,864	0	40,864	73,638
Charitable Activities	89,008	46,268	135,276	124,828
Governance	750	0	750	1,403
Prior Year adjustment				(1,489)
Total Resources expended	<u>130,622</u>	<u>46,268</u>	<u>176,890</u>	<u>198,380</u>
Net movement in funds	<u>198,641</u>	<u>6,832</u>	<u>205,473</u>	<u>6,933</u>
Reconciliation of funds				
Total Funds brought forward	<u>34,658</u>	<u>0</u>	34,658	<u>27,725</u>
Total Funds carried forward	<u>233,299</u>	<u>6,832</u>	<u>240,131</u>	<u>34,658</u>

Evelina Children's Heart Organisation Limited
Balance Sheet as at 31 December 2020

		31 December 2020	31 December 2019
		£	£
Fixed Assets	(Note 5)	0	0
Current Assets			
Debtors	(Note 6)	6,978	402
Cash at bank and in hand		238,757	37,223
Total Current assets		<u>245,735</u>	<u>37,625</u>
Creditors falling due within one year	(Note 7)	(5,604)	(2,967)
Net Assets		<u>240,131</u>	<u>34,658</u>
Funds of the Charity			
Unrestricted Funds		233,299	26,701
Restricted Funds	(Note 8)	6,832	0
Previous Year creditor written back		0	7,957
Total Funds		<u>240,131</u>	<u>26,701</u>

For the year ending 31 December 2020 the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

* The members have not required the company to obtain an audit of its accounts for the year in question in accordance with section 476

* The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts.

These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime

Chair 

P J WARD

Date:

05/07/2021

Evelina Children's Heart Organisation Limited
Notes to the Accounts

Note 1: Accounting Policies

The principal accounting policies are summarised below. The accounting policies have been applied consistently throughout the period.

Basis of Accounting

The financial statements have been prepared on the basis of the historic cost convention and in accordance with the Companies Act 2006 and the Statement of Recommended Practice - Accounting and Reporting by Charities (SORP 2005) issued in March 2005.

Fund Accounting

Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity. Restricted funds are subjected to restrictions on their expenditure imposed by the

Incoming resources

All incoming resources are recognised once the charity has entitlement to the resources, it is certain that the resources will be received and the monetary value of incoming resources can be measured with sufficient Grants and donations are included in the SoFA when the charity has unconditional entitlement to the resources and incoming resources from tax reclaims are included at the same time as the gift to which they Investment income is included when receivable.

Resources expended

Expenditure is recognised on an accrual basis as a liability is incurred.
Costs of generating funds are those costs incurred in attracting voluntary income.
Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its members. It includes both costs that can be allocated directly to such activities and those Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include independent examination fees and costs linked to the strategic management of the All costs are allocated between the expenditure categories of the SoFA on a basis designed to reflect the use of the resource. Costs relating to a particular activity are directly allocated.

Fixed assets

Tangible fixed assets are stated at cost less depreciation. Depreciation is provided at rates calculated to write off the cost less estimated residual value of each asset over its expected useful life as follows:-

Computer equipment - 33.33% straight line basis

Note 2: Trustees Remuneration

No remuneration was paid to the trustees in the 12 month period ended 31 December 2020.
No expenses were paid during the period.

Note 3: Analysis of incoming resources

**Total Funds
12 month period to
31 December 2020**

£

Voluntary income:

Unrestricted donations

325,778

Restricted donations

53,100

Gift Aid

0

Government JRS

3,347

Investment income:

Bank Interest

138

Total

382,363

**12 month period to
31 December 2020**

£

**Note 4: Analysis of
charitable activities**

Back Office/Admin

29,493

Volunteers

257

Information

6,300

Member Support

99,226

Total

135,276

Note 5: Fixed Assets

No fixed assets are owned by the company.

Note 6: Analysis of Debtors

	<u>£</u>
HMRC	<u>6,978</u>

Note 7 : Analysis of Creditors

<u>Accruals</u>	<u>£</u>
Trade creditors	2,586
PAYE, NIC	3,018
	<u>5,604</u>

Note 8 : Ringfenced Income

Balance B/F	0
Ringfenced Donations	53,100
Expenditure	(46,268)
Balance C/F	<u>6,832</u>



Independent examiner's report on the accounts

Section A

Independent Examiner's Report

Report to the trustees/
members of

EVELINA CHILDREN'S HEART ORGANISATION LIMITED

On accounts for the year
ended

31 DECEMBER 2020

Charity no

1145494

Set out on pages

1-7

Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144 of the Charities Act 2011 (the Charities Act) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the Charities Act,
- to follow the procedures laid down in the general Directions given by the Charity Commission (under section 145(5)(b) of the Charities Act, and
- to state whether particular matters have come to my attention.

Basis of independent examiner's statement

My examination was carried out in accordance with general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair' view and the report is limited to those matters set out in the statement below.

Independent examiner's statement

In connection with my examination, no matter has come to my attention 1. which gives me reasonable cause to believe that in, any material respect, the requirements:

- to keep accounting records in accordance with section 130 of the Charities Act; and
- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the Charities Act have not been met; or

2. to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Signed:

Melza H. Linfield

Date:

28th August 2021

Name:

MELZA LINFIELD FCA

Relevant professional qualification(s) or body (if any)

ICAEW

(if any):

Address: Danestone Business Services Ltd
52 Crown Drive
Inverness IV2 3QG

Section B

Disclosure

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.