



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

(A company limited by guarantee)

Charity Name Evelina Children's Heart Organisation Limited

Working name	ECHO
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Charity registration number 1146494

Company number 7867592

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

Chair Stephen Wood

Treasurer Alex Bicknell

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

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

- **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

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

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## 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 40<sup>th</sup> 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/](http://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

***"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."***

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.

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

**40<sup>th</sup> 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](http://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.

### 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.



**Black History Month Tea Trolley on cardiac ward**



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



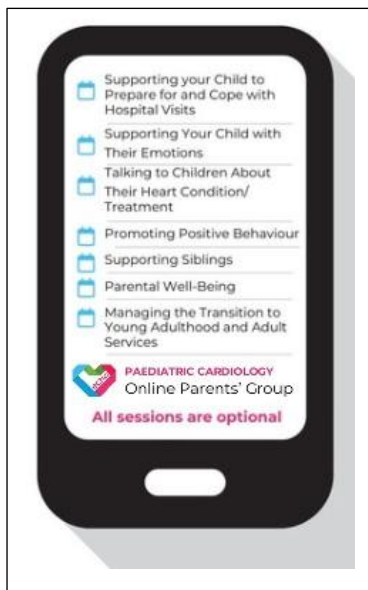


help the young people grow in confidence and social skills while enjoying themselves.

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.



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 play 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 **21<sup>st</sup> 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



**21<sup>st</sup> London CHD Course**





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](http://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 £
<b>Incoming Resources</b> (Note 3)				
Donations	215,321	111,773	327,094	320,782
Investment Income	4,649		4,649	3,380
Gift Aid	621		621	912
<b>Total incoming resources</b>	<b><u>220,591</u></b>	<b><u>111,773</u></b>	<b><u>332,364</u></b>	<b><u>325,074</u></b>
<b>Costs of Providing Charitable Activities</b> (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
<b>Total Resources expended</b>	<b><u>395,005</u></b>	<b><u>68,064</u></b>	<b><u>463,069</u></b>	<b><u>355,689</u></b>
<b>Net movement in funds</b>	<b><u>(174,414)</u></b>	<b><u>43,709</u></b>	<b><u>(130,705)</u></b>	<b><u>(30,615)</u></b>
<b>Reconciliation of funds</b>				
Total Funds brought forward	<u>207,318</u>	<u>77,248</u>	<u>284,566</u>	<u>315,181</u>
<b>Total Funds carried forward</b>	<b><u>32,904</u></b>	<b><u>120,957</u></b>	<b><u>153,861</u></b>	<b><u>284,566</u></b>

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

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

15<sup>th</sup> 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
<b><u>At 31 Dec 2024</u></b>	<b><u>23,573</u></b>
<u>Depreciation</u>	
At 1 Jan 2024	12,048
Charge 2024	6,518
<b><u>At 31 Dec 2024</u></b>	<b><u>18,566</u></b>
<u>Net Book Value</u>	
At 1 Jan 2024	8,405
At 31 Dec 2024	<b><u>5,007</u></b>

**Note 6: Analysis of Debtors/Prepayments**

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

**Note 7 : Analysis of Creditors**

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

**Note 8 : Unrestricted Designated Funds**

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

**Note 9 : Ringfenced Income**

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

### Management Accounts for 2024

<u>Income</u>	<u>£</u>
Donations	£327,094.00
Interest	£4,649.00
Gift Aid	£621.00
<b>TOTAL INCOME</b>	<b>£332,364.00</b>
<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
<b>TOTAL COSTS</b>	<b>£463,069.00</b>
<b>Excess Income/Costs</b>	<b>-£130,705.00</b>





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.

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