



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 pediatric 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:

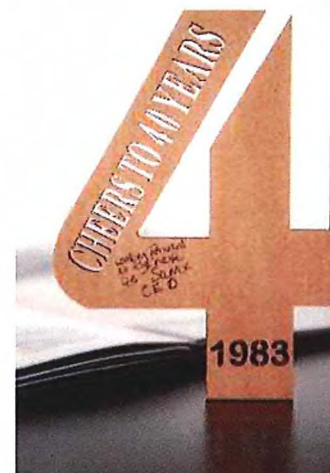
- Specialist antenatal classes, reducing anxiety and worries parents may have about the birth and their child's health. We fund a midwife team to run 9 classes each year online under the specialist care of the Thames Tower Midwives.
- ECHO Teens group provides information, support, and guidance for teens 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.

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.



Heartificial Intelligence exhibit

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)

"I opened a door to a community of people that understood my pain. **It was a huge lifeline... ECHO gave us hope,** something a lot of others outside the community couldn't!"

Haywards Heath
West Sussex

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.



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

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.

"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** 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 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:

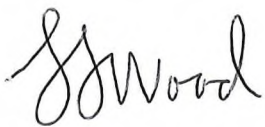
- Publish our next five-year strategy
- Engage with the wider ECHO community, with a commitment to being ever more inclusive
- Update the ECHO website and our cardiac support resources, including videos for key milestones in the CHD journey, to give families high quality information that builds their 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

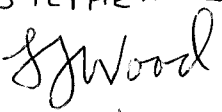
		31 December 2023 £	31 December 2022 £
Fixed Assets	(Note 5)	8,405	5,495
Current Assets			
Debtors/Prepayments	(Note 6)	5,008	13
Cash at bank and in hand		274,657	310,941
Total Current assets		<u>288,070</u>	<u>316,449</u>
Creditors falling due within one year	(Note 7)	(3,504)	(1,268)
Net Assets		<u>284,566</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
<u>At 31 Dec 2023</u>	<u>20,453</u>
 <u>Depreciation</u>	
At 1 Jan 2023	6,177
Charge 2023	5,871
<u>At 31 Dec 2023</u>	<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>
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	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	£325,074.00
<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	£355,689.00
Excess Income/Costs	-£30,615.00



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

Charity no.:

1146494

Company no.:

7867592

Set out on pages

1 - 7

(remember to include the page numbers of additional sheets)

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: Melza H. Linfield Date: 03.08.24

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.