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 2025 TO 31 DECEMBER 2025

Evelina Children's Heart Organisation Limited

(A company limited by guarantee)

Report of the Board of Trustee Directors for the Period 1 January 2025 to 31 December 2025

| | |
|---|---|
| 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 James Pincus

Trustees

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

Special Advisors to the Board

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

Staff

- Chief Executive Samantha Johnson
- Families & Community Lead Emma Orpin
- Income & Trust Coordinator Kate Smith
- Impact & Network Coordinator Vashti MacDonald-Clink
- Family & Volunteer Coordinator Marie Taylor
- Communications Coordinator Yasmin Badesha, Ethan Sheward – started 24/02/25, Mariam Akintokun started, 09/07/25, Connor Rosslee – started 25/09/25
- Youth Worker Andrew Edherue
- Engagement & Income Coordinator Lilly Mae Cinquemani - started 09/07/25

Leavers

- Fundraising Lead Rebecca Holt – left 17th April 2025
- Operations & Development Lead Cecilia Yardley – left 1st August 2025
- Communications Coordinator Yasmin Badesha – left 21st February 2025, Ethan Sheward – left 20th June 2025, Mariam Akintokun – left 14/08/25

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

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

## Letter from the Chief Executive – Samantha Johnson



A year of connection, change and growing our support for families
2025 has been a year of change, learning and opportunity for ECHO.

Above all, we have remained focused on what matters most: supporting children, young people and families living with congenital heart disease (CHD) and other childhood heart disease, from diagnosis and treatment through their hospital journey and into life in the community.

I am incredibly proud of what the ECHO team and our volunteers have achieved this year. Much of our work happens behind the scenes, but its impact is felt every day by the families we support.
One exciting development has been approval from E Synergy for a new kitchen at ECHO HQ, alongside improvements to our family room. These spaces will provide families with somewhere welcoming and practical to meet, talk, eat, rest and feel supported.

Our work with young people has continued to grow through our film project, sharing the experiences of young people navigating transition. These stories highlight the value of hearing from others who have faced similar challenges and will help young people feel less alone and better prepared for the next stage of their journey.

We have also strengthened our connections across the CHD lifelong network, creating films featuring staff from different parts of the service, including colleagues from Evelina, alongside families themselves. These will help families better understand the support available throughout the lifelong network.

Our relationships with clinical teams have continued to strengthen, including increased interaction with the Cardiac, Respiratory and Intensive Care (CRIC) teams across Royal Brompton Hospital and Evelina. Partnerships with Guy's and St Thomas' NHS Foundation Trust (GSTT), King's College London (KCL) and the School of Biomedical Engineering have also continued to connect our community with the medical, research and academic sectors.

Research and innovation remain important to our work. We continue to develop relationships with the HRC, KCL and other research and academic partners, supporting projects with the potential to improve understanding, treatment and experiences for the CHD community, while ensuring the patient and family perspective is represented.

ECHO were delighted to welcome two new Special Advisors to the ECHO Board. Saloni, a mum with lived experience of CHD and the patient pathway at Royal Brompton Hospital, and Karan, a patient with lived experience of CHD and a Chartered Accountant, bring valuable perspectives. Their contribution is helping us strengthen how lived experience informs our organisation and the way our Board listens and learns.

We have also strengthened ECHO's foundations. We upgraded our website and made the difficult decision to close the ECHO Forum as communication increasingly moved towards email, telephone and social media. New business cards for our specialist nurses, games and equipment for the play team, and clearer posters explaining ECHO and our referral process have helped families and professionals connect with us and better understand our role.

In December 2025, I took some time away from ECHO to celebrate my daughter's wedding. It was a very special time for my family and an important opportunity for me to pause, reflect and recharge. I strongly believe that wellbeing matters for everyone at ECHO, and I will continue to advocate for the wellbeing of our staff and volunteers. Their commitment, compassion and energy are at the heart of what ECHO achieves, and supporting their wellbeing is an important part of building a healthy and sustainable organisation.

**Looking ahead:** 2025 has been an important year for strategy and a significant period of change across children's cardiac services. A major development has been the decision that children previously treated at Royal Brompton Hospital will now receive their cardiac surgery and interventions at Evelina. This has already increased Evelina's caseload, and ECHO expects to support nearly twice as many families in the immediate term.

We have spent considerable time considering what this means for ECHO and how we ensure we are ready to support families through this change. Cranfield University and the British Heart Foundation (BHF) have supported us as we have worked through our strategic planning.

Not everyone will approach these changes in the same way, but ECHO has always believed in the value of working together. Our culture is one of collaboration, partnership and, above all, prioritising the needs of children, young people and families. We will continue to work constructively with clinical teams, NHS partners, researchers and others across the network to ensure families remain at the heart of what we do.

ECHO remains the only cardiac charity established specifically to support families treated by GSTT and its network hospitals. That focus gives us a unique understanding of the CHD journey and the capacity to provide the specialist, personalised support families need. Alongside clinical care, we bring what only we can offer — practical help, emotional support, peer connection and the family voice that shapes how care is delivered.

Our full focus on children's heart disease enables us to provide one-to-one support, accessible information and resources, and activities that promote emotional wellbeing and connection. Lived experience is fundamental to who ECHO is. The voices of patients and parents help shape our understanding, our services and the way we think about the future.

As the services around us change, ECHO's 43 years of experience supporting children, young people and families provides a strong foundation for the future. We know the CHD journey, we understand the needs of families and we know the value of working alongside others. Our priority is to continue providing trusted, independent and specialist support throughout that journey — while ensuring the voices and experiences of the families we serve remain at the heart of what we do.

Samantha

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

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

***"ECHO has been a lifeline for me"***

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

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

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

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

**Fundraising and community**

Fundraising has enabled us to do more for families. The incredible **Statom ball**, supported by around 30 volunteers, raised an amazing £117,000 for ECHO, helping fund new services including our reading programme, a family support coordinator and a major family event for next year. We are extremely grateful to Statom for their continued support and for sponsoring ECHO's first London Marathon team for 2026.

**esynergy** has also brought a wonderful burst of energy to the ECHO community, including our first Volunteer Day. Their team and partners created a very special Christmas gift initiative, buying, donating and wrapping hundreds of presents for children in hospital. Such was their generosity that the gifts will continue to support families at key times throughout the year, including Eid and Black History Month.

Our wider community has continued to grow *including those working at **Fenchurch Street** Insurance through events and personal challenges. The Chislehurst 1 in 100 Holes of Golf brought new people to ECHO and fundraising, while BMX Life has supported ECHO for more than 10 years, providing fun opportunities for families to be part of their community.

We have also seen individuals turn personal sporting and physical challenges into fundraising opportunities, while schools have embraced Wear Red and young people have taken on their own challenges through Twenty to Plenty. We are equally grateful to those leaving a legacy gift to ECHO, creating a lasting contribution for families in the years ahead.
We would like to give a very special thank you to Walter, who chose to leave ECHO a gift in his will. Team ECHO took part in a special memory-making moment to create a puzzle representing Walter's gift, which now proudly hangs in the ECHO office. We are incredibly grateful to be remembered in this very special way, and to know that Walter's generosity will continue to make a difference to children, young people and families in the years ahead.

Our festive Advent campaign brought hope, connection and fun to families, healthcare professionals and fundraising partners, while support from Joel Virgo Photography has helped capture the people and moments behind our work. Together, these contributions reflect the

generosity of the ECHO community and help us continue providing practical, emotional and specialist support to families.



## Supporting our team and wider community

We continued investing in team development, including bereavement support, safeguarding, risk assessment and social media training. Attending the BCCA helped colleagues connect with children's cardiology professionals across the UK, share experience and learn from new approaches.

We also joined Children's Heart Surgery Fund in Leeds and Children's Heart Unit Fund from Newcastle for shared learning, comparing approaches and recognising our common purpose despite different challenges.

We are proud to work within the wider CHD community alongside Little Hearts Matter, Max Appeal, Tiny Tickers, Somerville Foundation and HeartChild. Sharing knowledge strengthens our organisations and helps us better support children, young people and families affected by heart disease.

Children's Heart Surgery Fund & BCCA visits





## ECHO's 2025 Activities – Month by month

**January**

- Supporting your child to prepare and cope with hospital visits - the group provided a space for parents of children with a heart condition to share experiences and ideas with one another around supporting their child and family's emotional well-being.
- London Winter Walk – Allowed people the opportunity to walk either a full or half marathon, 10k or a Family Fun 5k!

ECHO teen event, ECHO Teen Filmmaking, Wear Red at Kettering Hospital






**February**

- ECHO Teens: Behind the Lens - our new project, led by multi-award-winning mobile cinematographer and filmmaker Cassius Rayner, where ECHO Teens will be creating two of their very own short films, one of which will be used in transition workshops across hospitals in the UK.
- Heart Month - we celebrated Heart Month with a special edition of our beloved Tea Trolley. Instead of our usual treats, we filled it with delicious, red-themed goodies, all in support of raising awareness for children's heart conditions. We also encouraged people to Wear Red for ECHO!

**March**

- The next three ECHO Teens: Behind the Lens sessions took place! One was online where they could develop their magical ideas and the next two were carried out in person. The final session provided our teens with opportunity of a residential stay overnight in London! – This residential trip was the highlight of Andrew's 2025 at ECHO!
- Supporting your child with their emotions – parent group where they could share experiences and ideas with one another around supporting their child and family's emotional well-being.
- Mother's Day - ECHO and MACE group created and delivered Mother's Day gift bags to those in the hospital.
- Eid Mubarak – ECHO and MACE group created and delivered hampers to those in hospital.
- Hampton Court Palace Half Marathon - The half marathon started and finished inside historical Hampton Court Palace. This epic event allowed our runners not only to run a half marathon for charity, but it also gave them entry into one of the UK's best historical attractions.

Eid hampers with Joy, Lena from Lambeth walking tours, Aaron Bell with Clare volunteer at London Zoo, Beth Edward Mansell






**April**

- BMX Life Bunny Hop 10 – A fun-filled BMX ride across London's iconic landmarks. We loved seeing everyone's bunny costumes!
- London landmarks half marathon – Our biggest team of runners yet! We had 16 runners fundraising for ECHO!
- Fenchurch insurance supported ECHO through helping to deliver Easter eggs to the children in the hospital
- London marathon – Simon ran the London marathon for ECHO and raised over £2,000 and completed the marathon in just over 4 hours
- We also had runners fundraising for us in the Brighton, Paris and Manchester Marathon
- Windsor Easter 50 Challenge – Runners could take on a 50 km Ultra, a historic 25 km, or a sharp 10 km challenge all through Windsor and along the Thames.

**May**

- ECHO Teens Awful Egyptians at Richmond Theatre
- London Zoo Adventure with ECHO -Over 80 families (300 people) joined us for a fun, relaxed adventure exploring the zoo, spotting incredible animals, and enjoying a sunny picnic together. We loved seeing everyone's pictures with Eddie as part of the Eddie On Tour challenge too!

Volunteer celebration at the Globe, Easter donations, Wear red in Feb & Eddie ECHO- Giving Eddie a voice for the animation






**June**

- ECHO at the House of Lords – The Importance of Play – ECHO attended the launch of the National Strategy for Play 2025 and the Raising the Nation Play Commission on the International Day of Play. Hosted by Baroness Anne Longfield, the event brought together parliamentarians and sector leaders to highlight the vital role of play in childhood. We met Sue Pruden, Head of Play at Evelina London, and joined the wider conversation about ensuring children living with heart disease have opportunities to play, build confidence, connect with others and simply be children.
- ECHO Stories – Our ECHO Stories launched in June, celebrating our 40+ year journey and the people who make up our community. Films featured families at home, telling their stories.
- Father's Day – We created and delivered special Father's Day gift bags to families in hospital.
- ECHO Teens – Wellbeing through Art – Teens took part in an online art workshop led by an experienced art therapist, using creativity to explore emotions, connect with others and support their wellbeing.
- Volunteer Celebration Event – We held our first volunteer celebration since COVID, welcoming 19 volunteers to the Globe Theatre. It was a special opportunity to recognise and celebrate the contribution of our volunteers.

1 in 100 golf day, Sue Pruden & CEO Rasing the Nation play, Lilly presents to Woolwich study day






**July**

- Chislehurst Hundred-Hole Charity Challenge – 12 people were part of Team 100 and (including Chair Steve Wood) took part in a golfing marathon! 100 holes of golf covering 26.2 miles in just one day. Team 100 raised over £17,000
- Lilly and Mariam started
- We launched the 'Twenty to Plenty' school holiday fundraiser. Allowing children to see what they can turn £20 into. Children who raised over £160 were thanked with a
- certificate, badge and ECHO wristband

**August**

- London Zoo
- ECHO Teens event – An event for our 18-25 group. This enabled young people aged 18 - 25 to meet others as well as help to shape the future of the new 18–25-year-old group.
- Weekend art challenge – Children under 18 were given the opportunity to design artwork to be displayed in the new Galaxy outpatient's clinic in the Children's Day Treatment Centre

**September**

- ECHO on the road: The team visited Leed's Children's Hospital to meet with the amazing Children's Heart Surgery Fund and our friends from CHUF (Children's Heart Unit Fund) Newcastle. Our teams came together to share learning, exchange ideas, and tour the hospital

- The Traitor's – Esynergy invited the team for a wonderful networking night! Lilly claimed victory as a faithful, Marie hanged in until the last round and unfortunately Sam was voted out last (she was too good at solving clues)
- Twenty to Plenty Holiday Challenge – over £1,000 raised.

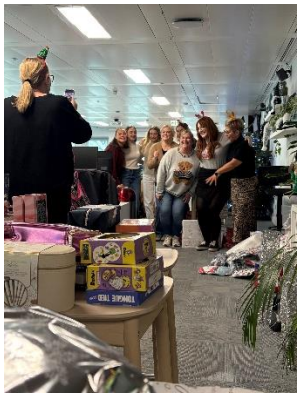
**October**

- BHM - our tea trolley was filled with items from businesses owned and run by people of Black heritage.
- Kent life farm family day - Over 150 people showed up for a fun and relaxed day filled with activities for all ages — from painting pots, terrarium making, feeding animals and even a foam party! We received support from Fenchurch Insurance and Enfinium and they helped to support the event and made sure it was possible that families could have an amazing time! - This was one of Lilly's highlights of her first year at ECHO!
- ECHO Teens – Transition Myth buster game – A virtual workshop to help break down any worries our teens may have with moving over to adult services

**November**

- ECHO Teens at enigma quests – the ECHO Teens had a day of cracking codes at enigma quests followed by pizza at pizza express
- Mystical Magical Tour – A gentle outing that occurred through the Southbank! This walk enabled families to step away from the hospital setting and to connect with other members of ECHO!

Festive trip out, Festive wrapping at esynergy, Festive BMX Santa Cruise


**December**

- Festive advent countdown: wonderful messages from different people who work for, with and are supported by ECHO.
- BMX Santa cruise 11 - The festive ride brought together an incredible BMX community, spreading Christmas cheer while they raised a staggering £18,320.43 for ECHO
- Statom charity ball – where the Statom group raised over £115,000 for ECHO

## Our people: Staff Highlights

**Kate:** "One of my biggest highlights of 2025 was seeing ECHO's income and fundraising grow and knowing that the funding I secured directly enabled us to continue and develop the support we provide to children, young people and families living with congenital heart disease.

From a fundraising perspective, I was really proud to bring in £148,557 through 24 successful awards and income streams during the year. Some particular highlights were securing £25,000 from the Garfield Weston Foundation and £18,900 from the National Lottery Community Fund."

**Vashti:** "My favourite moment was helping to bring Eddie ECHO to life through the animation – giving him a voice. It felt significant as this is one of the aspects of what we do, projecting the voice of our community – giving everyone a voice. It was an incredible project to work on from start to finish and it involved so many different people working in the area of congenital heart disease. Encompassing the views and ideas of teams working within the NHS alongside the CHD community who felt passionately about providing a resource around this unmet need for

young children with heart conditions. The animation brought about an addition to Eddies crew, Pru the bee. I'm looking forward to seeing where she takes us in 2026!"

**Emma:** "My fab moments from 2025 are having the privilege to visit families' homes and hear up close and personal how their CHD journey has looked. I am so proud of the films but more than anything I am proud to know such amazing families that continue to support ECHO and others throughout their own personal hard times.

**Sam and the Edward Mansell Room.** Huge thanks to all the young people who helped to provide Matt and the team from Gensler, who helped to create a relaxing space for young adults who have transitioned from children to adults. They didn't just design and provide- they came and did too. Thank you!











***A thoughtfully crafted room which blends soothing comfort with an uplifting energy. Inspired by tennis and the power of bouncing back, it supports young heart patients in rest, play, and recovery- where resilience and hope take centre court!"***

## ECHO's direct services to members in 2025

> ***"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

- **Membership growth** ECHO membership grew by 104
- **Website** (www.echo-uk.org), **publications, and video resources** on YouTube to provide guidance and reassurance and support decision-making.
- **Private Facebook Group** moderated by ECHO with 1,800 (increase of 200) 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' cardiac 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 provided specific services to the following groups:

| | |
|---|---|
| • Parents-to-be | • GSTT NHS Trust |
| • Young people aged 11-25 | • CHD Lifelong Network |
| • Children aged 0-10 | • Inpatients and their families |
| • Siblings of children with heart condition | • Families in the community |
| • Bereaved families | • Researchers and the research community |
| • Families impacted by congenital heart disease | • Third sector organisations |

## 2025 Case Study: Kent Life – Family Day report



### Introduction to the day

On 4th October 2025 ECHO held a family day at Kent Life Farm in Maidstone, Kent. The day was organised to give families from across the Lifelong Congenital Heart Disease (CHD) Network (covering London, Kent, Essex, Suffolk, Surrey, Sussex and further afield) a chance to spend time together away from the hospital or 'everyday' home life. Where they could meet other families affected by similar lived experiences without having to worry about planning or paying. They were provided with a fun, supportive and relaxing space where parents, carers, children and young people with heart conditions and also their siblings could meet and share stories, as well as take part in physical and well-being activities at their leisure. The event was advertised through our open and closed members social media platforms and email.

### The aims of the event were to:

Impact positively on ECHO members' mental health and well-being. Foster an enhanced focus among the ECHO community on their individual and family's emotional health, in a safe and fun environment, providing a shared space with families who are facing similar life challenges.

Activities included:

- Paint a pot
- Tractor ride
- Owl demo
- Cuddle corner/feed the animals
- Terrarium making
- Caricature drawing
- Massage and relaxation workshop

### Spotlight activity – Terrarium making

Connecting with nature is a well-known process to relieve stress and anxiety whilst boosting mood and improving focus. This workshop provided participants of all ages with an opportunity to access Nature Assisted Therapy through making their own Terrarium. This workshop was attended by 80 participants.

*The Nature-Assisted Therapy (NAT) approach sees nature as an active partner in the therapeutic processes through the use of plants, natural materials and encounters in natural outdoor environments (Annerstedt and Währborg, 2011, Corazon et al., 2010, Newcomb, 2019, Stigsdotter et al., 2011). The theoretical framework of the NAT is based on the sociological, psychological and ecological principles of Eco-Psychological Theory (Gornowicz, 2019, Roszak et al., 1995, Scull, 2008).*

*"We had such a fab time, the terrariums are pride of place on the kitchen windowsill with our painted pottery, and the memories will last a lifetime, thank you for a wonderful day"*

**Highlights**

The day was a great success. Over 35 families, with varying length of relationships with ECHO, came along and all were observed having a wonderful, active, and social day. In total 139 members attended from babies, a few months old, to adults. From long-standing members to those new to the charity, people came from near and far, with one family only having been discharged from the Evelina hospital 48hrs before the event.

Out of the staff and volunteers there was representation from individuals who have congenital heart disease (CHD) and those that have cared for children/young people with CHD, health professionals, alongside sponsors of the event and supporters of the ECHO.

**Some highlights of the day include:**

- The palpable excitement felt throughout the day – of seeing old friends, building new networks, trying new things, and doing fun things with the ECHO community.
- Families travelling from across the CHD network to attend the event in Kent – not just Kent-based families.
- Children and young people growing in confidence to participate throughout the day, with the support of our dedicated ECHO youth worker.
- New ECHO members connecting with longer-term families and more established families reconnecting and spending time together away from the hospital

*"The only people who really understand what I'm going through are my friends here"*

The quiet area in the village hall that provided calm and welcoming space in a warm and relaxed environment. Tables were set up with crafts; these proved to be very popular and were used by most families throughout the day. Families visibly relaxed and enjoyed time spent together – either engaging with their own families or with others – sharing stories and lived experiences.





There was 100% participation in the viewing of ECHO's new animation resource during the lunch hour. Children/young people with CHD and their siblings were asked to provide feedback on their feelings – before and after watching the animation. 58 responses were recorded in total, demonstrating strong engagement. Families gave positive feedback in response to viewing.

*"So great not to use the word 'blood', my son after all his blood tests can't use that word and panics. He calls the b-tests to help. Wonderful to see and animation that listens to children"*





**Did the day fulfil the aims?**

Being with other families, with shared or similar lived experiences, was stated many times as a key motivation for attending the event as they knew there would be 'lots of support', 'no judgement' and 'everyone would be in the same boat' - a situation many said was not a regular occurrence outside of ECHO events.

***"What an amazing day and team! The best family we could ask for thank you for being on this journey with us!"***

***"Loved spending time with other heart families and the ECHO family. Thank you, x,"***

There was a marked increase of 10% in attendance versus previous years which demonstrated the clear need for these kinds of events, focusing on wellbeing and community – the membership was drawn to the theme and the quality of events organised by ECHO.

***"Coming together as a team. Nothing to improve! What a special team at ECHO!!"***

***"A really relaxed environment as ever. You are worth your weight in gold and then some. Thank you, x,"***

***Best Part – "The atmosphere built by the Echo Team Throughout the day"***

Building such strong relationships with our members enables us to be in the great position we are, families developing this level of trust enables the flow of communication that results in us knowing how to positively impact in many areas of their lives. This enhances their general well-being. Events like this enable us to bring the wider community together to share thoughts, feelings and ideas. These are what then often fulfil a wider purpose, beyond the event itself – through learnings and experiences often new workstreams and resources are born.

This event also enabled families to directly feed into a health technology research project, which will help other families in their lived experience with CHD. Facilitating this collaboration with the wider CHD community is often very important to wellbeing as it gives people the opportunity to impact on change. There were over 80 responses to the questionnaire on the day.

The opportunity for children/young people to be active participants around their healthcare makes a big difference to outcomes, happiness and confidence. At this event they were actively involved, and their views were sought – throughout the day. When challenged to get involved with wide ranging activities they displayed the confidence to participate – if not instantly – with gentle encouragement.

***"I enjoyed painting a ladybird because I love animals. Thank you"***

## Financial Review – Reserves policy 2025

**Evelina Children's Heart Organisation Limited**
**Statement of Financial Activities**
**For the period from 1 January 2025 to 31 December 2025**

| | Unrestricted Funds Period Ended 31 December 2025 £ | Restricted Funds Period Ended 31 December 2025 £ | TOTAL FUNDS Period Ended 31 December 2025 £ | TOTAL FUNDS Period Ended 31 December 2024 £ |
|---|---|---|---|---|
| **Incoming Resources** | | | | |
| Donations | 320,157 | 93,457 | **413,614** | 327,094 |
| Investment Income | 2,810 | | **2,810** | 4,649 |
| Gift Aid | 3,999 | | **3,999** | 621 |
| **Total incoming resources** | **326,966** | **93,457** | **420,423** | **332,364** |
| **Costs of Providing Charitable Activities** | | | | |
| Cost of fundraising | 84,539 | | **84,539** | 107,854 |
| Charitable Activites | 159,727 | 186,314 | **346,041** | 354,431 |
| Governance | 834 | | **834** | 784 |
| **Total Resources expended** | **245,100** | **186,314** | **431,414** | **463,069** |
| **Net movement in funds** | **81,866** | **(92,857)** | **(10,991)** | **(130,705)** |

**Evelina Children's Heart Organisation Limited**
**Balance Sheet as at 31 December 2025**

| | 31 December 2025 £ | 31 December 2024 £ |
|---|---|---|
| **Fixed Assets** | 1,736 | 5,007 |
| **Current Assets** | | |
| Debtors/Prepayments | 2,943 | 2,011 |
| Cash at bank and in hand | 146,372 | 156,003 |
| **Total Current assets** | **149,315** | **158,014** |
| Creditors falling due within one year | (8,181) | (9,160) |
| **Net Assets** | **142,870** | **153,861** |
| **Funds of the Charity** | | |
| Unrestricted Funds | 114,770 | 32,904 |
| Restricted Funds | 28,100 | 120,957 |
| **Total Funds** | **142,870** | **153,861** |

## Letter from the Chair of the Board of Trustee Directors

Stephen Wood

### *A year of generosity, change and preparation*

Looking back over 2025, what stands out is the breadth of what this small organisation achieved and the generosity of everyone who chose to be part of it. Forty-three years after ECHO was founded, we remain the only cardiac charity established specifically to support families treated by Guy's and St Thomas' and its network hospitals. That focus, and the trust built over four decades, matters more than ever as we prepare for the year ahead.

Everything ECHO does begins with our members. This year our membership at a faster rate than ever before, our events continued to show the value of bringing families together: 139 members from more than 35 families joined us at Kent Life, while more than 80 families over 300 people came to London Zoo. These moments of connection are often where families find the understanding, reassurance and friendship they need most.

I want to record the Board's admiration for Samantha Johnson and the ECHO staff team. Much of their work happens quietly: conversations before consultations, listening in clinic, the weekly Tea Trolley, visits to the office near the Evelina, and support for families at every stage of the congenital heart disease journey. This year the team also developed new resources, strengthened bereavement support, upgraded the website, supported youth and transition work, and helped bring Eddie ECHO to life through animation and family stories – we love Pru our new character and one of Eddie ECHO's friends.

ECHO simply would not function without its volunteers. From the wards and family days to the Tea Trolley, mentoring and major events, they give time, experience and kindness when it matters. We were pleased to hold our first volunteer celebration since COVID, welcoming 19 volunteers to the Globe Theatre, and I offer my sincere thanks to every volunteer who supported ECHO this year.

The generosity shown to ECHO in 2025 was extraordinary. The Statom ball raised more than £117,000, funding new services and support for families, and Statom will sponsor ECHO's first London Marathon team next year. The BMX Life community raised £18,320.43 through the Santa Cruise, and runners, schools, families, corporate partners and community supporters all played their part. I am especially proud to have played 100 holes of golf on what ended up being the hottest day of the year at Chislehurst golf club, Team 100 raised over £17,000.

We are especially grateful to Walter, who chose to leave ECHO a gift in his will. The puzzle made in his memory now hangs in the ECHO office, and his generosity will be felt by families for years to come.

The year also brought difficult decisions and important preparation. We closed the ECHO Forum as families increasingly turned to email, telephone and social media, and we saw turnover within the team. Most significantly, the move of children's cardiac surgery and interventions from Royal Brompton Hospital to the Evelina is already increasing demand, and ECHO expects to support close to twice as many families in the immediate term. This will test our capacity, funding and people.

The Board has spent considerable time preparing for this, supported by Cranfield University and the British Heart Foundation through our strategic planning. We were also delighted to

welcome Special Advisors Saloni Thanki and Karan Panesar, whose lived experience and professional expertise are already strengthening how the Board listens and learns. My thanks go to James Pincus as Treasurer and to all my fellow trustees for the care and rigour they bring to their responsibilities.

To our members, staff, volunteers and supporters: thank you. What you achieved together in 2025 has put ECHO in a strong position to meet what comes next.

Steve

**Stephen Wood**

Chair of the Board of Trustee Directors




**Thank you to everyone across the ECHO community for helping, listening, joining and fundraising. We couldn't do what we do without you.**

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

Registered Charity number 1146494

Company Number 07867592

**ACCOUNTS FOR THE PERIOD FROM 1 JANUARY 2025 TO 31 DECEMBER 2025**

Evelina Children's Heart Organisation Limited
Accounts for the period from 1 January 2025 to 31 December 2025

| | |
|---|---|
| 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<br>Joanna Eyeson<br>Alex Bicknell<br>Stephen Wood Chair<br>Marc Harry<br>James Pincus |
| Independent Accountant | Danestone Business Services Ltd<br>52 Crown Drive, Inverness. IV2 3QG |
| Bank | CAF Bank<br>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 2025 to 31 December 2025**

| | | Unrestricted Funds Period Ended 31 December 2025 £ | Restricted Funds Period Ended 31 December 2025 £ | TOTAL FUNDS Period Ended 31 December 2025 £ | TOTAL FUNDS Period Ended 31 December 2024 £ |
|---|---|---|---|---|---|
| **Incoming Resources** | **(Note 3)** | | | | |
| Donations | | 320,157 | 93,457 | **413,614** | 327,094 |
| Investment Income | | 2,810 | | **2,810** | 4,649 |
| Gift Aid | | 3,999 | | **3,999** | 621 |
| **Total incoming resources** | | **326,966** | **93,457** | **420,423** | **332,364** |
| **Costs of Providing Charitable Activities** | **(Note 4)** | | | | |
| Cost of fundraising | | 84,539 | | **84,539** | 107,854 |
| Charitable Activites | | 159,727 | 186,314 | **346,041** | 354,431 |
| Governance | | 834 | | **834** | 784 |
| **Total Resources expended** | | **245,100** | **186,314** | **431,414** | **463,069** |
| **Net movement in funds** | | **81,866** | **(92,857)** | **(10,991)** | **(130,705)** |
| **Reconciliation of funds** | | | | | |
| Total Funds brought forward | | 32,904 | 120,957 | **153,861** | 284,566 |
| **Total Funds carried forward** | | 114,770 | 28,100 | **142,870** | **153,861** |

**Evelina Children's Heart Organisation Limited**
**Balance Sheet as at 31 December 2025**

| | | 31 December 2025 £ | 31 December 2024 £ |
|---|---|---|---|
| **Fixed Assets** | **(Note 5)** | 1,736 | 5,007 |
| **Current Assets** | | | |
| Debtors/Prepayments | **(Note 6)** | 2,943 | 2,011 |
| Cash at bank and in hand | | 146,372 | 156,003 |
| **Total Current assets** | | **149,315** | **158,014** |
| Creditors falling due within one year | **(Note 7)** | (8,181) | (9,160) |
| **Net Assets** | | **142,870** | **153,861** |
| **Funds of the Charity** | | | |
| Unrestricted Funds | | 114,770 | 32,904 |
| Restricted Funds | **(Note 8)** | 28,100 | 120,957 |
| **Total Funds** | | **142,870** | **153,861** |

For the year ending 31 December 2025 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 SSWood

Date: 29-9-26

**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 2025

| **Note 3: Analysis of incoming resources** | **Total Funds 12 month period to 31 December 2025 £** |
|---|---|
| *Voluntary income:* | |
| Unrestricted donations | 324,156 |
| Restricted donations | 93,457 |
| *Investment income:* | |
| Bank Interest | 2,810 |
| **Total** | **420,423** |

| **Note 4: Analysis of charitable activities** | **12 month period to 31 December 2025 £** |
|---|---|
| Back Office/Admin | 71,449 |
| Volunteers | 2,603 |
| Information | 22,761 |
| Member Support | 249,216 |
| **Total** | **346,029** |

**Note 5: Fixed Assets**

| | Fixed Assets |
|---|---|
| | £ |
| Cost | |
| At 1 Jan 2025 | 23,572 |
| additions | 1,045 |
| **At 31 Dec 2025** | **24,617** |
| | |
| Depreciation | |
| At 1 Jan 2025 | 18,565 |
| Charge 2025 | 4,316 |
| **At 31 Dec 2025** | **22,881** |
| | |
| Net Book Value | |
| At 1 Jan 2025 | **8,405** |
| At 31 Dec 2025 | **1,736** |

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

| | | £ |
|---|---|---|
| Prepayment : | Tax | 393 |
| | Prepaid expenses cards | 1,030 |
| | Rent | 1,520 |
| | | **2,943** |

**Note 7 : Analysis of Creditors**

| Accruals | £ |
|---|---|
| Trade creditors | 7,283 |
| PAYE, NIC, Pension | 898 |
| | **8,181** |

**Note 8 : Ringfenced Income**

| | £ |
|---|---|
| Balance B/F | 120,957 |
| Ringfenced Donations | 93,457 |
| Expenditure | (186,314) |
| Balance C/F | **28,100** |

**Management Accounts for 2025**

| **Income** | **£** |
|---|---|
| Donations | £413,614.00 |
| Interest | £2,810.00 |
| Gift Aid | £3,999.00 |
| **TOTAL INCOME** | **£420,423.00** |
| **Costs** | |
| General Admin | £34,960.00 |
| Fundraising | £23,134.00 |
| Promotional Items | £12,481.00 |
| Staff Costs | £285,649.00 |
| IT Costs | £12,952.00 |
| Charitable Activities | £55,410.00 |
| Volunteer Costs | £2,603.00 |
| Legal & Governance | £4,225.00 |
| **TOTAL COSTS** | **£431,414.00** |
| **Excess Income/Costs** | **-£10,991.00** |

CHARITY COMMISSION FOR ENGLAND AND WALES

# Independent examiner's report on the accounts

## 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 31/12/2025.

**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 H. Linfield **Date:** 19 SEPTEMBER 2026

**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**. | |