



EVELINA CHILDREN'S HEART ORGANISATION LIMITED

(A Company Limited by Guarantee)

Registered Charity Number: 1146494

Company Number: 7867592

REPORT OF THE BOARD OF TRUSTEE DIRECTORS

FOR THE PERIOD 1 JANUARY 2020 TO 31 DECEMBER 2020

Evelina Children's Heart Organisation Limited

(A company limited by guarantee)

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

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

Board of Trustee Directors

Chair: Jane Ward

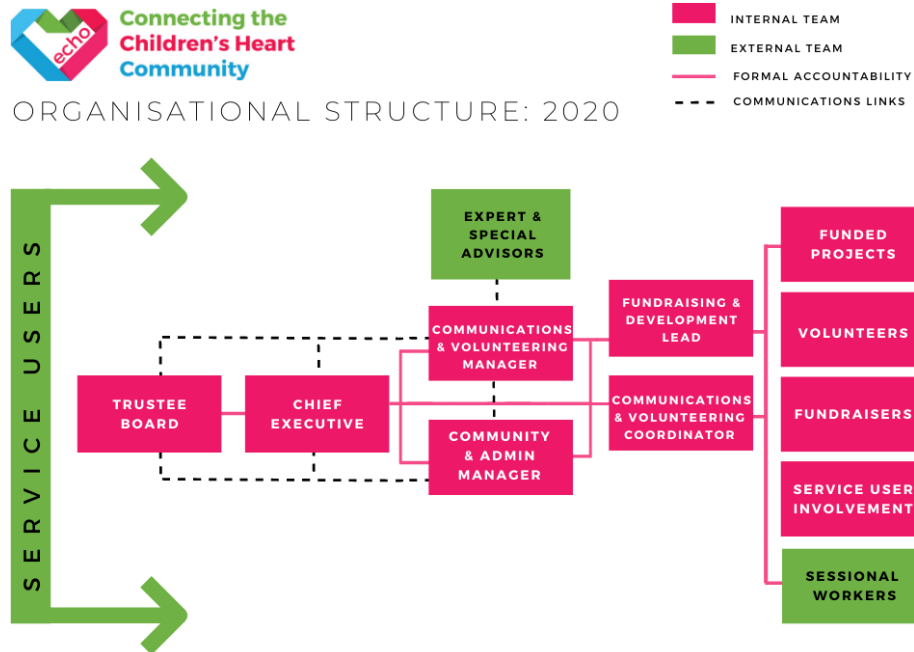
Trustees:

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

Staff:

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

ECHO organisational structure – 2020



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

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

Our mission, vision and values:

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

About ECHO:

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

professionals. ECHO is regarded by many as a second family and a strong network to be part of at all life stages of the CHD journey. Often people access support in a crisis and again years later at different milestones.

Who we support:

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

How ECHO supports heart families:

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

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

COVID-19 Crisis & ECHO's Response

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

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

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

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

ECHO's services:

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

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

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

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

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

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

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



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

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

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

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

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

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

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

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



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

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

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

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



Media & Communications

Website

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

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

In response to the ECHO cardiac antenatal class moving online and parents facing unprecedented isolation while in hospital, ECHO expanded our [cardiac antenatal resources](#) including messages from parents, advice on what to take with you to hospital, and a guide to the neonatal unit.

2020 newsletter mailout

Reflecting on 2020, we sent **2,300** ECHO member families an end of year postal newsletter with a printed card featuring word art of the important words which came up within the ECHO heart community during the onset of the COVID-19 pandemic. 'Challenging', 'Isolating' and 'Scary' were some of the words used, but amongst the fear we were also part of some amazing resilience and strength.



The newsletter featured stories from members of the ECHO heart community about their experience during the COVID-19 pandemic including Evelina London cardiac staff, ECHO families, fundraisers, volunteers and trustees. We saw the wonderful ways people in the cardiac community supported each other and our online groups and volunteers supported those who needed it quickly, reducing isolation and fear.



Festive Fortnight

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



Fundraising & Events

Heart Month Party

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



Bloom & Grow community workshop

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



Cancelled events

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

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

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

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

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

Online events

Breakfast with ECHO & alpacas

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

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

Virtual games night

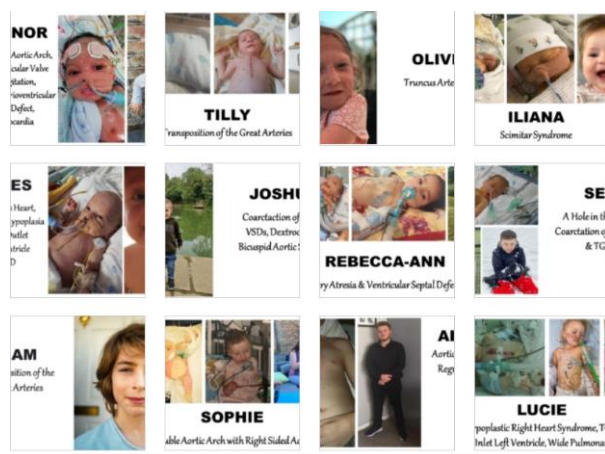
*In July, ECHO supporter Gary and the BNI Keane network held an online **Spectacular Gameshow Mashup**, inviting people to donate and enjoy a night of online games as we all navigated a world without face to face fundraising events.*

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

1 in 100 campaign

In summer 2020, **77** ECHO members from across the country, all supported by ECHO and treated by the Evelina London Cardiac Team, are featured in a parent-created #1in100 music video appeal to raise awareness and vital funding to help other children with heart conditions. Families shared their personal experience of Congenital Heart Disease in order to support new families receiving a diagnosis and showing the public the story behind the journey. The 77 children featured in the appeal video *I Am Home*, sung by Byron and the Stratford East Singers,

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



2.6 Challenge

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

Secret Santa appeal

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

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



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

Yeo Valley Award

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

ECHO Team

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

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

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

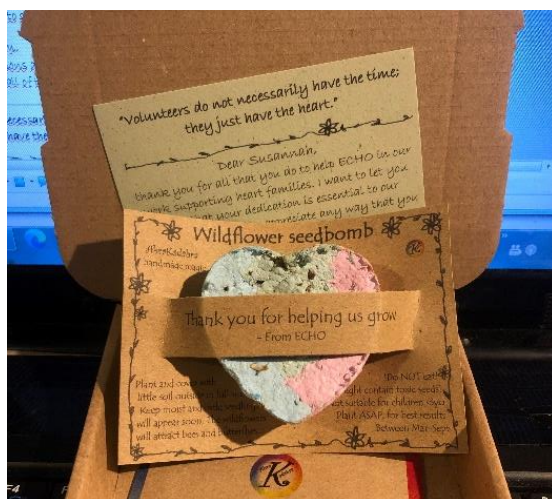
Volunteers

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

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

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

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



ECHO member story

Tracy's story:

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

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



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

Financial Review

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

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

Trusts & Foundations

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

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

Relationships

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

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

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

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

Stay at Home with Scientists

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

'Echoes' heartbeat app

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

Kings College London, Health Psychology Masters Placement Programme:

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

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

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

House Committee – Evelina Ronald McDonald House:

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

Patient Parent Voice – Evelina CHD Network:

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

BNI Networking:

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

CHD Charity Network Meeting:

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

CHARLOTTE, ECHO ambassador

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

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

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

Southbank University

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

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

Looking forward to 2021

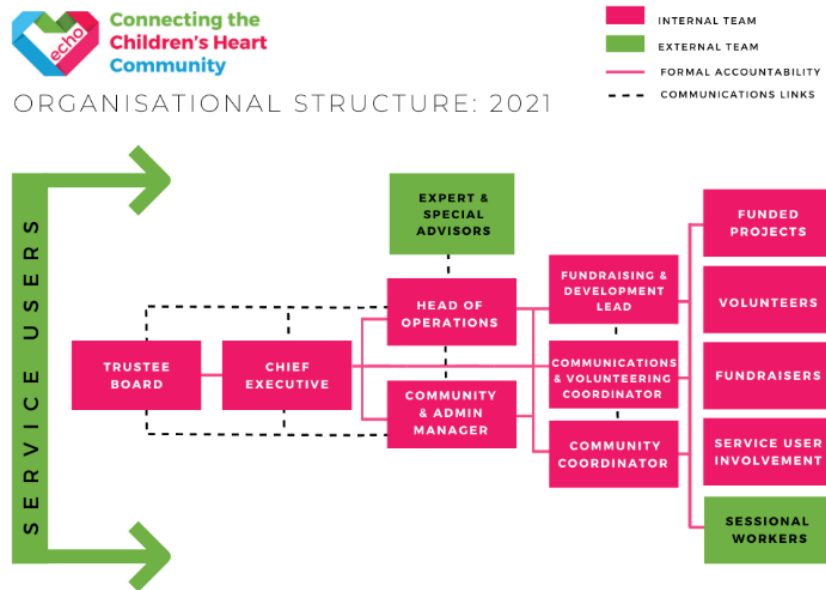
- We are excited to launch a monthly **ECHO Teens Film Club** in 2021 - for young people aged 11-17 with a heart condition and their siblings. Young people will be able to learn filmmaking skills from professionals, have fun and connect with other young people.

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

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

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

ECHO organisational structure – 2021



Structure, Governance and Management

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

Recruitment and appointment of trustee directors

The directors of the company are also charity trustees for the purposes of charity law. Under the requirements of the Memorandum and Articles of Association the trustee directors must retire at the first Annual General Meeting (AGM) and subsequently each trustee director may be elected to serve for a period of three years after which they must be re-elected at the next AGM. The minimum number of trustee directors is 5 and there is no maximum. The trustee directors can be appointed in general meeting or by the other directors. Questions arising at a meeting shall be decided by majority votes. The trustee directors are responsible for the general control and management of the charity. They give their time freely and receive no remuneration or other benefits. Any expenses

reclaimed from the charity are set out in the accounts. The trustees meet approximately every 12 weeks (this has been more frequent during the COVID-19 pandemic) and are responsible for decisions made in relation to the running of the charity. Members of the committee may join alternate meetings. Any trustee director may call a meeting of the trustee directors provided reasonable notice is given.

Risk management

The trustee directors have assessed the risks the charity faces and has put in place policies to manage the risks. For example, the charity has plans in place to protect against a downturn in the level of our income, finances are kept under review, Disclosure and Barring Service (DBS) checks are made, all members of staff have a contract of employment and comprehensive staff handbook which outlines all terms and conditions of employment and staff and volunteers working directly with children, young people or vulnerable adults are DBS checked. In 2019, we worked with Tom Searle of Britrisk Safety Limited to run risk assessment training to ECHO staff and reviewed our Health and Safety & organisation's Risk Policy.

Declaration

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

Jane Ward

EVELINA CHILDREN'S HEART ORGANISATION

(A company limited by guarantee)

Registered Charity number 1146494

Company Number 7867592

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

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

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

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

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

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

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

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

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

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

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

Chair 

P J WARD

Date:

05/07/2021

Evelina Children's Heart Organisation Limited
Notes to the Accounts

Note 1: Accounting Policies

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

Basis of Accounting

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

Fund Accounting

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

Incoming resources

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

Resources expended

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

Fixed assets

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

Computer equipment - 33.33% straight line basis

Note 2: Trustees Remuneration

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

Note 3: Analysis of incoming resources

	Total Funds 12 month period to 31 December 2020 £
<i>Voluntary income:</i>	
Unrestricted donations	325,778
Restricted donations	53,100
Gift Aid	0
Government JRS	3,347
<i>Investment income:</i>	
Bank Interest	138
Total	<u>382,363</u>

Note 4: Analysis of charitable activities

	12 month period to 31 December 2020 £
Back Office/Admin	29,493
Volunteers	257
Information	6,300
Member Support	99,226
Total	<u>135,276</u>

Note 5: Fixed Assets

No fixed assets are owned by the company.

Note 6: Analysis of Debtors

	£
HMRC	<u>6,978</u>

Note 7 : Analysis of Creditors

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

Note 8 : Ringfenced Income

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



Independent examiner's report on the accounts

Section A

Independent Examiner's Report

Report to the trustees/
members of

EVELINA CHILDREN'S HEART ORGANISATION LIMITED

On accounts for the year
ended

31 DECEMBER 2020

Charity no

1145494

Set out on pages

1-7

**Respective
responsibilities of
trustees and examiner**

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

It is my responsibility to:

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

**Basis of independent
examiner's statement**

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

**Independent
examiner's statement**

- In connection with my examination, no matter has come to my attention
1. which gives me reasonable cause to believe that in, any material respect, the requirements:
 - to keep accounting records in accordance with section 130 of the Charities Act; and
 - to prepare accounts which accord with the accounting records and comply with the accounting requirements of the Charities Act have not been met; or
 2. to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Signed:

Melza H. Linfield

Date:

28th August 2021

Name:

MELZA LINFIELD FCA

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

ICAEW

(if any):

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Address:

Danestone Business Services Ltd

52 Crown Drive

Inverness IV2 3QG

Section B

Disclosure

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

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

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