

ECHO

Impact Report 2017

Our mission is to make a
difference to the lives of heart
children and their families.



Introduction

2017 has been a milestone year for us at ECHO (Evelina Children's Heart Organisation).

- We opened our first office – based opposite the Evelina London Children's Hospital and St Thomas' Hospital we now have space for members, staff and families, including a parent's resource room; a meeting room for training sessions and workshops, plus ample storage for hospital resources we provide.
- We celebrated the 2nd anniversary of our cardiac family support service, which delivered 440 hours of direct cardiac support to families and 91 hours of home visits.
- We ran our #ImproveOurRooms campaign and raised over £4,600 to help decorate the Parent's Room on the Savannah Ward at Evelina London. Our corporate supporters Whitehead Monckton Solicitors made a large financial contribution and sent volunteers to help redecorate.
- We grew our volunteer team, delivering an incredible 1,472 hours of volunteer's time across 2017.
- We held the first of our sibling groups at the ECHO office, supported by the Rainbow Trust Cardiac Support Worker, to give heart siblings a place to discuss their feelings while enjoying arts and crafts with other young people.
- We re-launched our branding, revitalising ECHO's messaging to communicate our key values of being resilient, empowering, supportive, open and honest, resourceful and impactful.
- Our new website was recognised by the Good Web Guide as 'Highly Commended', (alongside some really big charities) so we are very happy and thankful to design company Considered Creative for all their work helping us to achieve our goals.



Samantha Johnson
Chief Executive, ECHO
samantha@echo-uk.org

For our members, ECHO is not simply a charity – it is a community. We are endlessly grateful for the time and contributions that our donors, partners, parents, volunteers, hospital staff and children have given to ECHO, and we look forward to the years ahead together.

Who we are

From our founding in 1983 until today, ECHO (Evelina Children's Heart Organisation) has been run according to the best interests of children with heart conditions and their families.

ECHO provides support to families who have been treated by Evelina London Children's Hospital networks, and are there for them at all stages, from the moment of diagnosis throughout any treatment and care pathway or bereavement.

ECHO is regarded by many as a second family and a strong network to be part of throughout their congenital heart disease journey, as often people access support in a crisis and again years later at different milestones.

We offer practical and emotional support often when there is little other help available, bringing together children, young people and families, medical professionals into a community of shared experience and understanding.



Who needs us?

Professionals

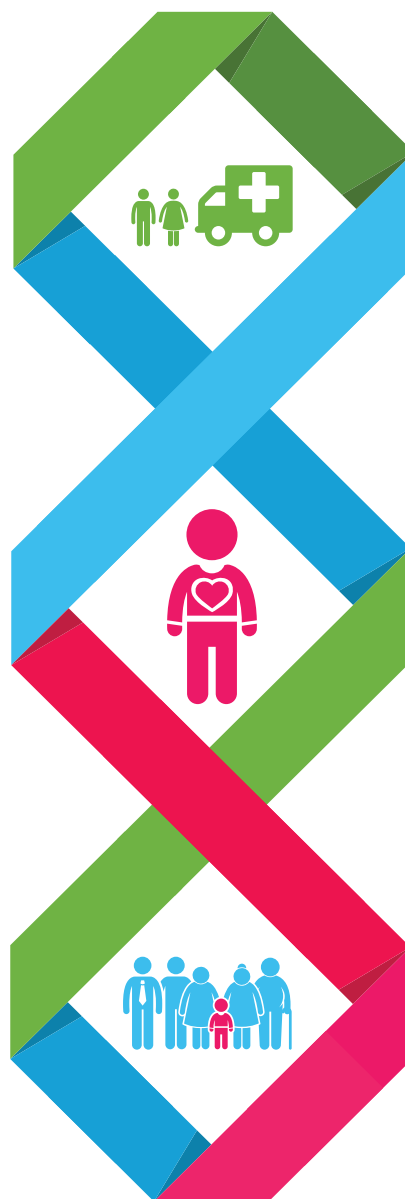
We have built and maintained strong relationships with medical, nursing and professional teams within Evelina London networks. We work with clinical staff to support in coordinating events, supporting families and providing resources to the hospital.

Siblings

Having a sibling with a heart condition can be tough so siblings living with a heart child are also supported from birth to 19. Siblings are welcome to all our family events and we support them in any way they need.

Parents and carers

From prenatal diagnosis, throughout their child's life, or whenever they need our services, we provide continuous support to parents and carers.



Children and Young People

We know how vital continued support is throughout the lives of children with heart conditions, at every age, so we support children and young people at every stage of their heart journey.

Wider family and friends

Fostering understanding of what heart families are going through is crucial for sustainably extending support networks amongst wider family and friends of ECHO members.

ECHO in numbers



new members per year



active volunteers



in annual donations



volunteer hours



**members of our
online support group**



events held in 2017

What makes our approach different?



We envision a world where the emotional, social, financial and medical needs of heart families are fully met and believe that our community can make this possible. Above all else we value resilience, empowerment, support, openness and honesty and enable these to flourish through our services. ECHO receive no government or NHS funding and rely on the generosity of our supporters to continue our work.

Throughout our 34-year history, we are proud to have helped thousands of families and have built ongoing strong relationships with medical, nursing and professional teams within the Evelina London networks.

Every ECHO family has a unique story, but they all know what it is to be touched by congenital or acquired heart disease. Our parents and young people tell us the only people who truly understand what they are going through are other heart families.

We are a small staff team yet support over 2,000 families annually and achieve multitudes through our incredible volunteers who devote their time to supporting the ECHO community through offering up parent-to-parent support; running local community events; sharing their story and much more. The majority of our volunteers are heart parents who want to give back to the community which supported them when they were in need.

The congenital heart disease journey may be daunting and seem insurmountable but our continuous encouragement day-to-day and in times of crisis helps to smooth the way.

“Going along for my 20-week scan was exciting. I never expected it to be the hardest day of my life. I went along to the ECHO Antenatal Class, and was reminded that it was OK to enjoy being pregnant and felt prepared for what was about to happen. Being in a room with other couples going through the same thing was amazing.”

ECHO parent

Our strategies to impact lives

Our services are built to provide information, friendship, support and guidance to children, young people and their families at times of need, from pregnancy through to childhood and into adulthood.

Parent-to-parent support

Our experience has shown us that parents of heart patients are often best placed to support similar parents. We have trained and supported parents to provide emotional and practical help in hospital, on the phone and by email, and in the community. Parents tell us that relationships built with other parents of heart children can have an enormous impact on their emotional wellbeing.

Cardiac Family Support Worker

2017 was our second full year funding the UK's first Cardiac Support Worker to provide significant lasting support to families experiencing extreme difficulties. This support strategy aims to bridge the gap between the medical care that families receive in hospital and the social care they receive in the home or community, improving families' emotional and physical wellbeing.

Our Cardiac Support Worker ensures she makes the biggest possible impact by prioritising cases based on need and being flexible and reactive to families' needs. In practice this means varying family contact from monthly trips with children or siblings, to significant involvement in families during times of high need.

"It can be hard explaining things to your own family and friends, but the heart community at ECHO just get it. We're like a big family that are bonded forever."

Jane - ECHO member

Support strategies to impact lives

♥ **Cardiac antenatal classes**

By funding the UK's only bespoke cardiac antenatal classes we have changed the lived experiences of pregnancy for parents whose unborn child has been diagnosed with a heart condition. The classes, which support around 200 parents each year, are facilitated by members of the Tower Midwife team, are run similarly to regular antenatal classes but focus on the specific needs and worries of these parents.

For many parents, these classes are the start of their relationship with ECHO and other parents of heart children. These classes and the relationships built leave parents feeling more prepared, supported, and confident ahead of the birth.

🏥 **Provide hospital resources**

ECHO has adapted to the constraints on NHS funding and stepped in to provide support where feasible and impactful. This year we have worked closely with Evelina London Children's Hospital to provide hospital support packs to parents at key times including comfort packs for those arriving at hospital by emergency ambulance; 270 pregnancy packs for parents who have had a recent antenatal cardiac diagnosis, and discharge packs for families of children recently discharged from hospital. This low cost intervention transforms children and parents' experience in Evelina London Children's Hospital by increasing fun, reassurance and comfort.

"The support from ECHO to produce these packs is invaluable. It immediately demonstrates the close working relationship between ECHO and Evelina London Children's Hospital Cardiology department to new families entering the cardiac fold and introduces them to the support they can expect in future."

**Louise - Fetal & Paediatric
Cardiology specialist,
Evelina London.**

Support strategies to impact lives

Our services are built to provide information, friendship, support and guidance to children, young people and their families at times of need, from pregnancy through to childhood and into adulthood. We pursue 12 key strategies of support in order to have the greatest impact on our families.



Sibling support

We recognise that having a sibling with a heart condition can be difficult for children and young people to understand and cope with. We run bespoke sibling days where siblings learn to understand and talk openly about their own feelings. ECHO also runs arts & crafts days during the school holidays to give siblings a change of scene and enhance their wellbeing.



ECHO Teens

Young people with heart conditions are invited, with their siblings, to join ECHO Teens. This improves the lives of heart teenagers and their siblings by providing information and support, as well as holding events and activities designed especially for teenagers. ECHO Teens events allows heart children to participate in events they may otherwise be unable to, improving emotional wellbeing and boosting confidence.

ECHO provided constant support and advocacy and helped to ensure our family maintained as much normality as possible for our older son. ECHO saw us as a family, and gave us support as a family, and that has made all the difference to all of us.”

Emma, ECHO member

Support strategies to impact lives

Heart community events

Events are held across the South East to facilitate families of children with heart conditions to form supportive friendships and access support. This year's ECHO Christmas party was hosted at Millwall football club for 400 people. ECHO community events make a huge difference to parents and children by allowing them to enjoy themselves and meet one another, knowing they are in a safe and supportive environment.

Provide information & resources

After receiving a Patient Information Award from the British Medical Association in 2015, we have strived to continue improving our provision of valuable information and resources to families. Through partnerships with experienced professionals, we provide information via our website, leaflets, social media, newsletters, DVDs and books for children. This ensures the widest possible reach.

Bereavement services

Some families have to face the devastating loss of a child. For these families we offer bereavement support for the whole family and can signpost to other organisations that can provide additional support. In 2017 we held a Bereavement Coffee Hub where bereaved parents came together to an informal gathering to have a coffee and a chat with people who understand the heartache they are going through.

Parent Facebook group

This online space, managed by ECHO, allows heart parents to meet and discuss their stories and concerns as well as share advice with one another.

ECHO journey through the ages



We provide a wide range of support throughout the journey of all members of heart families.

Parent Facebook group

Information & resources

Sibling support

ECHO Teens

Heart community events

Music therapy

Cardiac antenatal classes

Cardiac Family Support Worker

Parent-to-parent support



What we achieved



Connecting the
Children's Heart
Community

200

parents
attended
antenatal
classes

440

hours of cardiac
support to
families

91

hours of home
visit support
for heart
families

1,472

total volunteer
hours

177

1:1 music therapy
sessions held

22

people jumped
out of a plane.
Raising £10k
for ECHO

41

ECHO events
held

17

siblings
attended
Sibling Day



Our aims for 2018

In the next year, we want to:

- Develop our funding bids to provide support to teenagers with heart conditions and their siblings.
- Increase our music therapy sessions offered at Evelina London Children's Hospital.
- Introduce our ECHO Teens with a series of Hubs and events, offering more opportunities for young people with heart conditions and their siblings to meet, have fun and share experiences.
- Recruit two new trustees to join the ECHO team.
- Expand our website resources for our members such as information about disability living allowance.
- Review our training and support which we offer to our volunteers.
- Build communities by holding local events for heart families to meet others locally to them.



How you can help

Discovering your child has a potentially life threatening heart condition is one of the hardest things any parent can hear.

Children with heart conditions often face an uncertain future, where medical tests and treatment become normality. Many families find it difficult to cope and welcome additional support – which is where ECHO comes in.

Your support makes our work possible.

Donate: Your donation could help provide a comfort pack to parents arriving at Evelina; help us run community events to bring families together and share information; fund our Cardiac Support Worker to visit families, and much more.

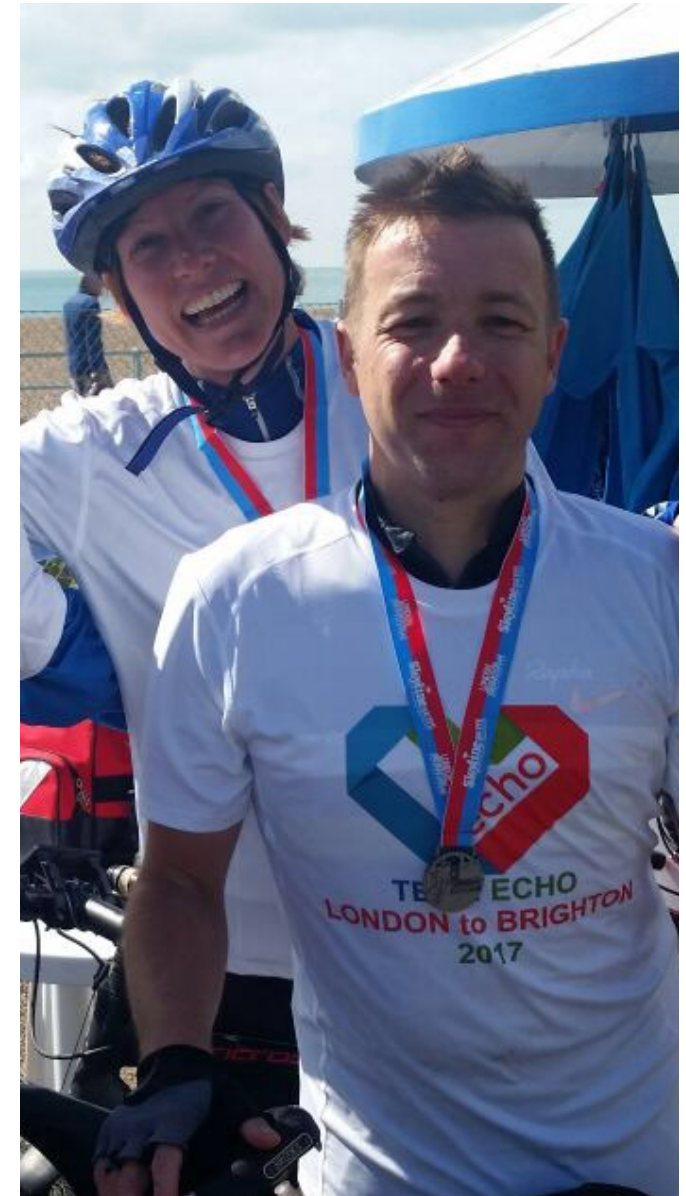
Fundraise: There are lots of great ways to fundraise from sponsored walks to office raffles, cake sales to once-in-a-lifetime travel challenges. You can even create your very own bespoke fundraiser!

Volunteer: Our volunteers are essential to everything we do – we simply could not support the ECHO community without them. We advertise roles on our website but you can also get in touch to find out other ways you can give your time to support heart families.

Get in Touch

hello@echo-uk.org | www.echo-uk.org | [f](#) [t](#) [i](#) [@echoukcharity](#)

ECHO, Canterbury House, 1 Royal Street London SE1 7LL.
ECHO is a Registered Charity No. 1146494



Trustee report

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

Chairs

David Philpott (Nov 2016 - ongoing)

Trustees

James Pincus

Patricia Jane Ward

Alex Bicknell

Joanna Eyeson

Mark Kennor

Stephen Wood (Jul 2017 - ongoing)

Marc Harry (Oct 2017 - ongoing)

Staff

Chief Executive

Samantha Johnson

Community & Administration Manager

Emma Orpin

Volunteering & Communications

Manager

Siobhan Morton

Fundraising Officer 10th October Start

Hayley Winter

Independent Accountant

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

Banker

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



Trustee report

Staff and new office

The ECHO team is made up of Samantha Johnson, CEO; Siobhan Morton, Communications and Volunteer Manager; Hayley Winter, Fundraising Officer and Emma Orpin, Community and Admin Manager. Use has also been made of sessional staff, especially in the ECHO Teen area of our work. Tania has run ECHO sessions and will continue to do so over the coming year. Diana has also continued her role as Cardiac Support Worker, a role co-funded with the Rainbow Trust charity.

This year, ECHO is pleased to have opened its first office, a space within minutes' walk of the Evelina London Children's Hospital. The space will also offer a relaxed room for families.

Rebrand

Leading the rebrand and development of the new ECHO website and resources, Samantha Johnson, ECHO's CEO, worked hard alongside Siobhan to ensure the ECHO story was clearly told, so members can access support more easily when needed and fundraising would be more attractive to larger companies and trusts.

Financial Review

In the past ECHO has been content to operate services for parents and children in a consistent way. If we are to continue to innovate new services, additional funding will be necessary to enable these to be provided. We will review our strategy and write a plan for the coming 5 years, including communications, support, fundraising and how to best reach members with changes possible to the London and national children's heart surgery provision across the NHS.

Structure, Governance and Management

Governing document

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 a majority of 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 together approximately every 6 weeks and are responsible for decisions made in

relation to the running of the charity. Members of the committee may join alternate meetings. Any trustee director may call a meeting of the trustee directors provided reasonable notice is given.

Risk management

The trustee directors have assessed the risks the charity faces and has put in place policies to manage the risks. For example, the charity has plans in place to protect against a downturn in the level of our income, finances are kept under review, Criminal Records Bureau 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 are DBS checked.

Declaration

The trustee directors declare that they have approved the trustee directors' report above.

Signed on behalf of the charity's trustee directors:

David Philpott

Chair of Trustees



A special thank you...

...to our funders and supporters.

We appreciate the time and contributions that our donors, partners, parents, volunteers, hospital staff and children have given to ECHO.

You are important to the success of ECHO and we look forward to working with everyone in the upcoming years.

We need your help.

You can now donate and find out about volunteering online via our website.

hello@echo-uk.org

www.echo-uk.org

[f](https://www.facebook.com/echo.uk) [i](https://www.instagram.com/echo.uk) [t](https://www.tiktok.com/@echo.uk) @echoukcharity

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