

echo: our story

Making a difference to the lives of heart children and their families.



Connecting the
Children's Heart
Community

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welcome to the **echo** story

**echo is not simply a charity - it is a community.
 A community of shared experience and understanding.**

All echo members know what it is to be touched by congenital & acquired heart disease in some way, and whilst every family's story is unique there are often similarities.

echo parents comment that the only people who truly understand what they and their children are going through are other heart parents.

The young people we work with also speak about how they enjoy spending time with others who understand them.

echo is here to support heart families on their individual journey, from diagnosis in pregnancy through to a child's adult years.

Exactly how we support families has been under review over the last two years. During this time we have explored all areas of the charity - and sought to strengthen the work we carry out. We've made some big changes, including rebranding echo and opening the 1st echo office opposite the Evelina London Children's Hospital.

The sole aim of any recent changes has been to improve our support to echo members.

In this document we aim to tell you where the charity came from, where it is now - and where it aims to be in the future.



We want to do what is best for our members, if you have any suggestions please get in touch.

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



echo: the beginning

echo was formed in 1983 by Dr Michael Joseph, the first Paediatric Cardiologist at the Evelina London Children's Hospital, together with parents of children with heart conditions. It came about from a desire to provide families with emotional support, as well as medical. Often parents felt lonely and isolated, having no one to speak to except medical staff.



The Joseph Brothers

Dr Michael Joseph and his brother Peter, a successful businessman, raised over £600,000 towards the first Paediatric Cardiology department at the Evelina Hospital, and to establish echo - the Evelina Children's Heart Organisation.

In its early years the charity focused on bringing together parents of children with heart conditions, for emotional support through a shared understanding.

Over the years the charity has been led and supported by parents & relatives of children who have travelled the congenital & acquired heart disease journey. We are still very proud to have parent representatives on our board and within our staff and volunteer teams.

We have built and maintain strong relationships with medical, nursing and professional teams within the Evelina London networks and are proud to have two respected medics as our patrons.

It is clear that the support echo provides today would not have been possible without the pioneering Joseph brothers, as well as the hardworking parents, volunteers and staff who helped to establish and grow the charity.



echo today

Over the past four decades echo has grown in size, and also in the range of support it provides.

From the moment of diagnosis, throughout any treatment and care pathway or bereavement, echo support children and young people with heart conditions and their families, who have received treatment at the Evelina London Children's Hospital.

We aim to support members from across the UK and do so both within the Evelina London, local general hospitals and throughout the community.

Congenital heart disease is the most common birth defect and affects just under 1 in 100 babies born throughout the UK. The range of conditions and treatments available mean that for children and parents the treatment pathway can be very different to anyone else they might meet with CHD.

echo receives no government or NHS funding and relies solely on public generosity to ensure that we continue to support and empower children, young people and families affected by heart disease.

Our mission

To support the children affected by heart disease & treated by the Evelina London Children's Hospital networks and their families.

Our vision

A world where the emotional, social, financial and medical needs of heart families are met.

Our values

Resilient, Empowering, Supportive, Open and Honest, Resourceful, Impactful.

"echo's work is hugely important. With ongoing reviews and potential restructures to NHS provision for CHD children, echo's role is pivotal in providing a critical friend to the Evelina London and its' peripheral clinics and to offering support to children"

Richard Parsons, Chairman of echo Trustee Board 2010-2016

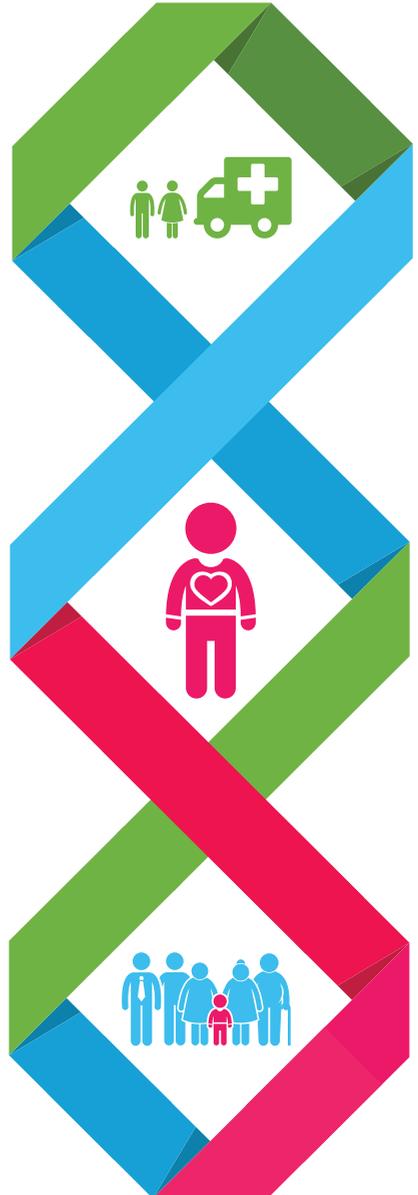
echo is regarded by many as a second family and a strong network to be part of at all life stages of the CHD journey by members, often people access support in a crisis and again years later at different milestones.

We are told by echo members that diagnosis and discharge from hospital can feel isolating, terrifying and at times impossible. Looking ahead and seeing others dealing with medical and social needs as they come up, as well as living day-to-day-life, offers encouragement to many while they face difficult experiences.

“echo have been amazing and supported us both through the worst two weeks of our lives”

echo parent

Those patients, families and carers a little further along the CHD journey are often best placed to offer peer-to-peer support. We train, develop and support local members to become volunteers and support others.



who **echo** supports

echo provides support to:



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



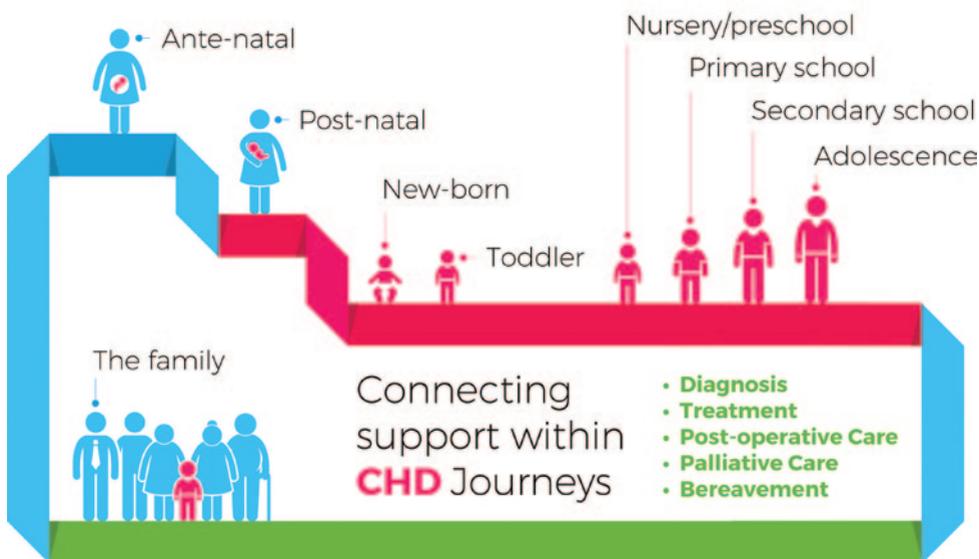
Wider family
who support echo members



Professionals
surrounding families at the Evelina
London and networks

"There's no denying it was a really tough time, but with the support of family and friends including echo you get through it."

echo parent



echo members today

We support the families of children who have been treated at the Evelina London Children's Hospital – and also at 19 peripheral clinics within the Evelina London's networks. The majority of echo members are spread throughout the South-East and as far away as Northern Ireland.

UK Surgery Centres

1. Alder Hey Hospital, Liverpool
2. Birmingham Children's Hospital, Birmingham
3. Bristol Children's Hospital, Bristol
4. Evelina London Children's Hospital, London
5. Freeman Hospital, Newcastle-Upon-Tyne
6. Glenfield Hospital, Leicester
7. Great Ormond Street Hospital for Children, London
8. Leeds General Infirmary, Leeds
9. Royal Brompton Hospital, London
10. Southampton General Hospital, Southampton

Scottish, Welsh & Northern Irish Units

1. Royal Belfast Hospital for Sick Children, Belfast
2. Royal Hospital for Children, Glasgow
3. University Hospital of Wales, Cardiff

Evelina Peripheral Clinics

1. Conquest Hospital, St Leonards-on-Sea, East Sussex
2. Darent Valley Hospital, Dartford, Kent
3. East Surrey Hospital, Redhill, Surrey
4. Eastbourne Hospital, Eastbourne, East Sussex
5. Epsom Hospital, Epsom, Surrey
6. Frimley Park Hospital, Frimley, Surrey
7. Ipswich Hospital, Ipswich, Suffolk
8. Kent & Canterbury Hospital, Canterbury, Kent
9. Kingston Hospital, Kingston-Upon-Thames, Surrey
10. Princess Royal University Hospital, Orpington, Kent
11. St George's Hospital, Tooting, London
12. The Tunbridge Wells Hospital, Pembury, Kent
13. University Hospital Lewisham, Lewisham, London
14. Queen Elizabeth Hospital, Woolwich, London
15. Q.E. The Queen Mother Hospital, Margate, Kent
16. Southend University Hospital, Southend, Essex
17. Royal Alexandra Hospital, Brighton, East Sussex
18. West Suffolk Hospital, Bury St Edmunds, Suffolk
19. William Harvey Hospital, Ashford, Kent



Once parents become members of echo they are able to access the wide range of support provided, free of charge. Young people aged 11-19 can be part of echo teens and receive specific information and updates.

Members are informed of upcoming events, hospital & charity news, and important updates via a monthly e-newsletter, yearly printed newsletters and on our website and social media channels.

Find out more or subscribe to our newsletter online

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

how **echo** supports heart families

Cardiac Family Support Worker

echo is funding the UK's first cardiac family support worker to help heart families who are experiencing extreme difficulties.

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.

Information & Guidance

echo provides valuable information and advice to help families on their heart journey via our website, leaflets, social media, newsletters, DVDs and books for children.



Antenatal classes

echo fund the only bespoke cardiac antenatal classes in the UK - 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/carer experience.



Discharge Packs

Specialist information for families discharged from hospital.



Comfort packs

When children are admitted to the Evelina as an emergency, parents often arrive with nothing. echo provide comfort packs for parents in this situation, containing practical help at a time when nothing else is available.

“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. I was reminded that it was ok to enjoy being pregnant and felt prepared for what was about to happen, being in a room with 8 other couples going through the same thing was amazing.”

echo parent

Music Therapist

echo funds a Music Therapist at the Evelina London Children's Hospital two days every week.

Support for Siblings

echo provides additional support for siblings, including an annual echo Sibling Day gathering, & information and guidance designed specifically for siblings.

echo teens

echo has an established group for young heart patients and siblings, echo teens. As well as providing information & guidance echo teens also organises fun activities, and helps young people transition to adult hospital services.

Bereavement Support

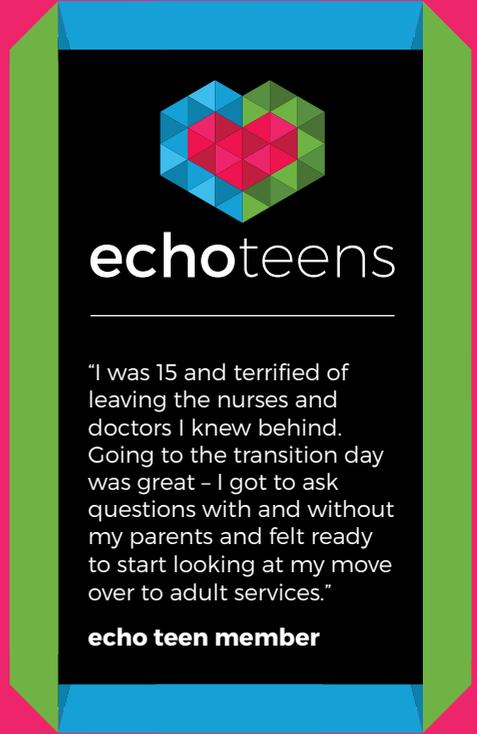
In the case of bereavement echo provides additional support for families in the form of group counselling sessions and remembrance gatherings.

Toys & Crafts

echo regularly provide toys and crafts for children on the wards of the Evelina London Children's Hospital.

Equipment which cannot be provided by the NHS

echo regularly provides small equipment to the Evelina London Children's Hospital that cannot be funded by the NHS.



echo teens

"I was 15 and terrified of leaving the nurses and doctors I knew behind. Going to the transition day was great – I got to ask questions with and without my parents and felt ready to start looking at my move over to adult services."

echo teen member

Emergency Accommodation

echo sponsors a room for families at Ronald McDonald House every year, providing emergency accommodation whilst children are staying in hospital.

Events

echo organise a number of events for heart children, their parents and siblings. These events help to reduce isolation, improve local support networks and also enable families to meet others who are experiencing a similar situation.

echo and the Evelina London Children's Hospital

As an independent charity, echo has an excellent working relationship with the Evelina London Children's Hospital. We partner with the hospital to provide trained volunteers on the wards, cardiac antenatal classes, sibling workshops, and transition days for young people moving into adult care.

We also purchase equipment for the wards which is not funded by the NHS, and arts & crafts for children in hospital.

In addition we provide a vital patient voice to help Guy's & St Thomas' NHS Trust shape its service for congenital heart disease.

As an independent and critical friend to the Evelina cardiac teams we will campaign, challenge and work towards the best possible services and outcomes for echo members and the wider congenital heart community.

We also work hard to ensure that the Evelina London can communicate changes to patients, families and the wider CHD community and that patient centred care is always considered.

The Evelina London Children's Hospital was rated as 'Outstanding' by the Care Quality Commission, with children's community services rated 'Good', in 2016. It is the only children's hospital in England to have been rated as 'Outstanding' by the CQC to date. Community services rate in the top 33% of children's community services nationally.

"Since taking on the Clinical Lead/Head of Service role for Paediatric & Fetal Cardiology, I have gained an increasing appreciation of the role played by echo in all facets of congenital heart care here at the Evelina London. As a Consultant here at the Evelina I have always relied heavily on echo as a point of contact and support organisation, particularly for families of patients who have just received a diagnosis of congenital heart disease. I have been impressed by the feedback I get from patients about their contact with echo in this very difficult time. echo is a strong partner in delivering high quality care directly to patients and families."

Dr Owen Miller FRACP, FCSANZ, FRCPCH
Consultant in Paediatric and Fetal Cardiology, Head of Service/
Clinical Lead, Evelina Director of Specialist Networks & echo Patron

echo in the community

We work hard to engage with our members both within the hospital and within their local communities.

We do this by organising local events, training volunteers to support families within their local region, and also by providing support through the Evelina's 19 peripheral clinics (local hospitals).

Treatment and care can feel very different when families leave the specialist surgical centre and need help locally. Families gain support from talking to and connecting with people who have experienced a similar journey to them.

You'll never know how it feels to watch your baby be put to sleep knowing there is a chance you'd never see her smile again, unless you've been there. I wouldn't wish it on anybody. But she was a fighter that day and got through!

echo parent



echo advocacy

echo advocacy work includes being part of the ongoing NHS England Standards Specification for CHD Review, which is tasked with reviewing the UK wide CHD surgical service to ensure that all units are of a high standard.

We also represent member's views within various campaigns including issues such as benefits and travel grants awarded to families affected by CHD, how children are supported in schools and what support is available nationally.

echo works alongside and in partnership with many local and national heart support groups and charities, ensuring we are aware of the national issues and best practices that may affect members of the CHD community.



Changes due to be implemented under the new Standards

echo welcomes the NHS England's set of congenital heart disease standards and service specifications.

echo aims to work closely with members on patient and parent engagement in this area, communicating changes or development clearly, and will be reviewing the geographical areas of our support to best fit with our purpose.

"The number of children born with CHD is expected to rise, as the birth rate rises. The number of operations and other interventional procedures has been increasing at three to four times the rate of population growth, and this is expected to continue."

NHS England



Volunteer and fundraise for **echo**

Volunteering

Our volunteers are a vital presence on the wards of the Evelina London Children's Hospital, and they also provide emotional support from home via the telephone and email, and in their local communities.

Many of our volunteers give their time by helping to organise echo events, strengthening the echo community and bringing fun and enjoyment to children with heart conditions.

Our volunteers are also our chief protagonists, sharing our work with the wider world and often being called upon to speak about the echo experience at schools, businesses and community events. Our volunteers are essential to everything we do - without them we simply could not support the echo community.

Fundraising

echo is financed entirely by donations. We receive no government or NHS funding. Every year generous individuals take part in all kinds of challenges, events and activities to raise money for echo.

In recent years we've had people BMX ride around London dressed up as Santa Claus, abseil down the Olympic Orbit and Guys Tower, pound the pavements of London in the Marathon, travel across sand2land, shave heads, throw garden parties and even eat every meal with chopsticks for a whole month - all to raise money for echo.

We also work with corporate partners and value each and every organisation who get involved with our work- many holding "dress down" days, charity of the year events, cycle rides, quiz nights, fun treasure hunts and golf days on our behalf.

Without the ongoing support of hundreds of simply outstanding fundraisers echo would not have been able to help the many thousands of families it has supported since it began. Our charity needs your help to support even more members in the future. If you would like to volunteer or fundraise for echo please contact: hello@echo-uk.org

The new **echo** brand

**echo is not simply a charity, it is a community.
Our new brand is designed to reflect that.**

During our review process it became clear that as an organisation echo needed to improve the way we tell the echo story, to encourage more families to join our organisation and receive support.

Our decision to re-brand has not been about changing echo. It has instead focused on what echo truly is. echo connects the children's heart community by bringing together children and young people with heart conditions, their families and medical professionals. It is a community of shared experience and understanding.



The new logo design encapsulates a colourful paper chain, demonstrating the unique way echo connects **children and young people, family and friends** and **medical professionals**.

echo**teens**

In addition to revitalising the echo brand we have also delivered an exciting new brand for young people, an evolution of echo teen club. **echo teens** reflects its position as an independent, vibrant space for young people with heart conditions, whilst remaining an important part of the wider echo community.



echo**teens**

The new **echo** office

In 2017 echo is proud to open its first office, opposite the Evelina London Children's Hospital.

As well as acting as the charity's head office the new space offers up:

- A parent's resource room: a quiet, comfortable, private space for parents when needed, complete with soft furnishings and access to a computer
- A bright and welcoming space for training sessions, bereavement workshops, large meetings and gatherings
- Ample storage space for equipment required by the hospital such as comfort, welcome, discharge and pregnancy packs

The future for **echo**

Over the next three years we will set about ambitious changes, aiming to make a big impact as a small charity.

We have recently taken an extensive review of echo and formulated a 3-year strategy, based on what people affected by CHD have told us they want to see in their lives. In developing and implementing our strategy we listened to a range of people – people with CHD, professionals, carers, volunteers, staff and others; as well as drawing on our own knowledge and research.

The strategy has clear outcomes:

- Improved access to relevant information
- Easy access to peer-to-peer support and other families on the CHD journey
- Better understanding of the condition and lifestyle issues associated with it
- Funds to sustain long term services
- Fun, friendship and family time is provided for children and young people
- More capacity for patients and families to access support at all milestones on CHD journey
- Increased understanding of transition from paediatric to adult services
- Reduction of isolation in hospital and in the community
- Access to advocacy and liaison with professional teams to raise the parent/patient voice

Working towards achieving our strategic aims will also enable echo to better demonstrate the way our organisation makes a difference, lead on partnerships and diversify income.

We will look at expanding the geographical area that we support, campaign for the best services for CHD families and reduce the impact on families going through the CHD journey.



“Members needs are and always will be at the heart of everything we do.”

**Samantha Johnson,
Chief Executive, echo**

“echo is very open and resourceful, I love going to them with ideas as they just seem to make it happen.”

echo parent

How to survive being a parent of a heart child

'Pessimism of the intellect, optimism of the will'

"This involves knowing all the contacts and the safety nets, finding out the institutional systems even if you never need them, and then getting on with life secure in the knowledge that you are prepared if things get scary.

If you have friends or relatives who are useful for leaning on, lean on them. And we have found great comfort in other parents – they know the feelings so you don't have to explain."

Heart parent and founding member of echo

"Our staff and trustees have a broad range of professional skills and expertise spanning medical, psychology, finance, social care, charity sector, the NHS, business, marketing and personal CHD. They come from diverse backgrounds but share a deep commitment to helping people touched by congenital heart disease."

David Philpott, Chairman of echo Trustee Board

Patrons: Dr Owen I Miller FRACP FCSANZ FRCPCH, Professor Shakeel A Qureshi MB ChB, FRCP, Ulrika Jonsson, Phil Gallagher

Registered address: Canterbury House, 1 Royal Street, London SE1 7LL

Registered charity, no: 1146494

hello@echo-uk.org

www.echo-uk.org

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