

# echo

## Impact Report 2016

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



# Who we are

**From our founding in 1983 until today, ECHO has been run according to the best interests of children with heart conditions and their families.**

We were created initially for parents to facilitate support networks with each other. Their similar experiences and shared understanding create fundamental emotional support in addition to pre-existing medical support. With time our range of services has expanded, touching the lives of thousands affected directly or indirectly by congenital and acquired heart disease. We know that discovering your child has a potentially life threatening heart condition is one of the hardest things any parent can hear. Many families find it difficult to cope and welcome additional support, which is why ECHO exists.

ECHO stands for Evelina Children's Heart Organisation as our roots are at the Evelina London Children's Hospital. London is our epicentre, with 19 peripheral hospitals in the South East of England. However, ECHO is also a test that most children with a heart condition will have in hospital too.

Having a recognisable name helps us to stand out within the heart community and enables us to raise awareness throughout society.



# Who needs us?

## Professionals

We have built and maintained strong relationships with medical, nursing and professional teams within Evelina London networks.

## 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.

## Parents and carers

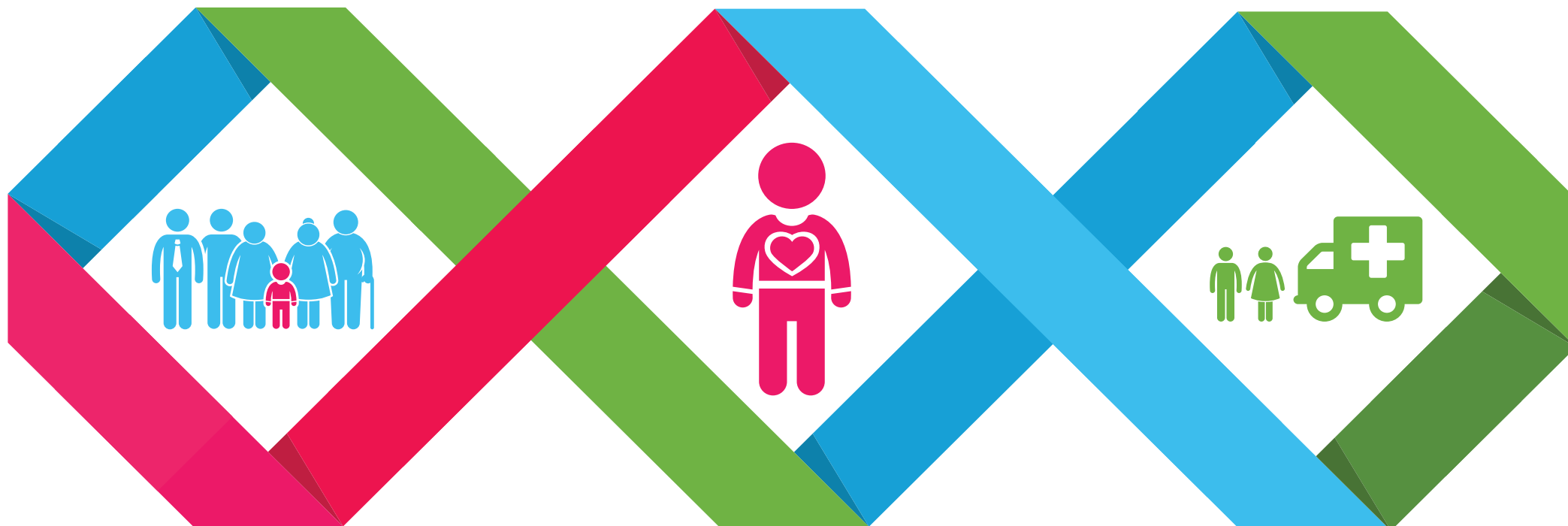
From prenatal diagnosis, throughout their child's life, or whenever they need our services, we provide continuous support to parents and carers.

## Children and Young People

We know how vital continued support is throughout the lives of children with heart conditions, from birth to 19.

## 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.





**new members per year**



**active volunteers**



**in annual donations**



**volunteer hours**



**families supported annually**



**events held in 2016**

# What makes our approach different?

**In 2016, Evelina London Children's Hospital was the first and only children's hospital in England to have been rated as 'Outstanding' by the Care Quality Commission.**

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.

We currently support over 4,500 families annually and enrich their lives by taking on the role of what many see as a second family. The CHD journey may be daunting and seem insurmountable but our continuous encouragement from day-to-day and in times of crisis helps to smooth the way.

"Being a volunteer with ECHO, you get to work as a team and support families and children, showing them that they're just like other kids and that most heart problems don't have to be treated as a disability to hold them back. I've been doing this for about 6 years and love the chance to make a difference."

**ECHO volunteer**



# 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.

## **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**

2016 was our first 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.

"Lots of parents have suffered loss and we all support each other without judgement. I find such strength being part of ECHO. We all have feelings in common and share information because we all trust each other."

**Jane**

# 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, 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 provided parent comfort packs as well as specialist play, medical and practical equipment, helping to alleviate stress and discomfort for children receiving medical treatment.

This low cost intervention transforms children and parents' experience in Evelina London Children's Hospital by increasing fun, reassurance and comfort. This year, ECHO has also intervened to directly improve the physical health of heart children by purchasing 4 Doppler machines for the hospital.

"Attending 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 eight other couples going through the same thing was amazing."

**Antenatal class parent**

"We were also very grateful to receive an ECHO Comfort Pack when we first arrived, containing little useful bits and pieces like shampoo etc. We were miles from home, and having had no prior warning we had barely anything with us. I was so touched to think someone had taken the time to put this together – the whole situation felt so surreal. I was getting excited about a tube of toothpaste."

**Sarah**

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## **Music therapy**

ECHO has pursued innovative ways to improve the experience of children receiving medical treatment in hospital. ECHO's fully qualified music therapist visits patients in the Paediatric Intensive Care Unit (PICU) and Savannah Ward (the specialist cardiac ward for babies, children and teenagers). The majority of referrals are for the under fives who often haven't developed the skills to articulate their feelings yet and so benefit hugely from this kind of psychological support.

## **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.

"My daughter was so afraid of being in hospital and the painful tests but then Cathy arrived, she looked forward to her weekly session so much and got out of bed each time for her, even after surgery... although this therapy may not fix bones or mend a heart it did help to rebuild by daughter's spirit."

**Mother of toddler on  
Savannah Ward**

# Support strategies to impact lives

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## **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. These events make a huge difference to parents and children by allowing them to enjoy themselves, 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. Throughout 2016 we held United in Grief events where bereaved parents came together to share their experiences, or just listen.

## **Parent Facebook group**

This online space allows parents to meet and discuss their stories and concerns as well as share advice.

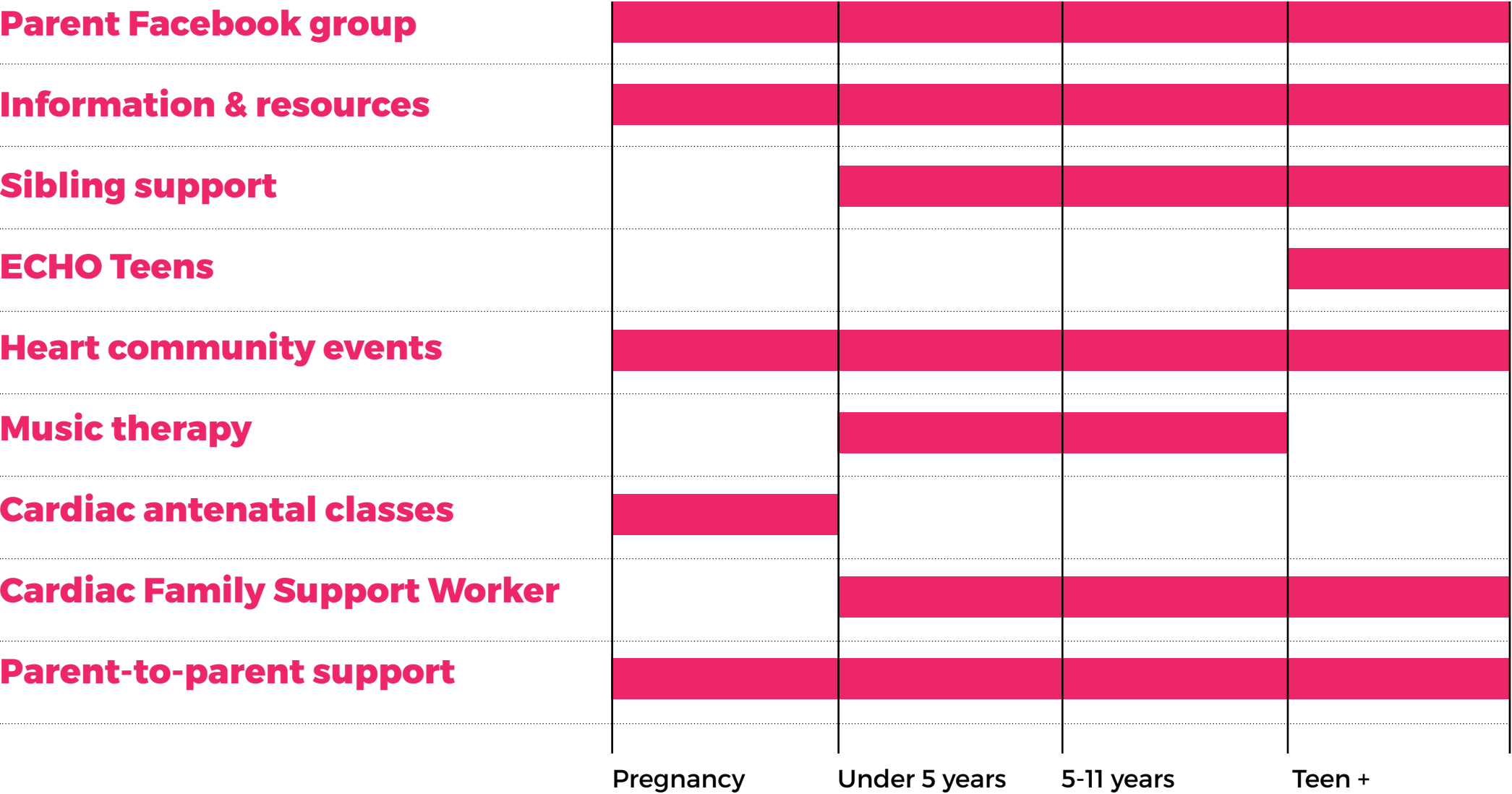
## **Emergency accommodation**

In 2016 we sponsored a room in Ronald McDonald House. This removes stress for families with children in hospital and allows them to spend more time with their children.

# echo journey through the ages



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



# What we achieved



Connecting the  
Children's Heart  
Community

**240**

parents  
attended  
antenatal  
classes

**155**

hours of cardiac  
support to 20  
families

**100**

home support  
visits for heart  
families

**851**

total volunteer  
hours

**189**

music therapy  
sessions with  
56 children

**23**

families referred  
to ECHO for  
family support  
services

**21**

ECHO events  
held

**16**

siblings attended  
Sibling Day



# Our aims for the next year

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**We want to have an even greater impact and have committed to helping even more families over the next year.**

In spite of being a small charity, we aim to have a big impact and are committed to making ambitious changes. We will always work with members to provide the service they need and value the relationships we have with them.

**Streamlining** our monitoring and evaluation capacity in order to understand our impact and create a sustainable framework to apply in the future.

**Maintaining** and strengthening levels of volunteer support in local communities and throughout the peripheral hospital network.

**Developing** our fundraising capabilities to include more trusts & foundations, companies and online sales.

**Raising** our profile by increasing the work we do with our patrons and friends of ECHO.

**Enabling** a strong collective voice for all members and CHD families, e.g. setting up focus groups for parents and teenagers.



# 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](mailto:hello@echo-uk.org)

[www.echo-uk.org](http://www.echo-uk.org)

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

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