

MEMBERSHIP FORM

To join ECHO, please complete the form below and return to:

ECHO P.O. Box 5015, Brighton BN50 9JR.

Alternatively, you may e-mail admin@echo-evelina.org.uk
or call **07943 625031**.

Name/s _____

Address _____

Telephone number _____

Email address _____

Baby's due date | |

Delivered at ST. Thomas'? YES NO

If not where? _____

Have you attended an ECHO antenatal class? YES NO

To speak to a Prenatal support volunteer or for more information,
please call **07943 625031** or email
prenatalsupport@echo-evelina.org.uk

Contact ECHO
To visit our website, please type in www.echo-evelina.org.uk
ECHO P.O. Box 5015, Brighton BN50 9JR
Registered Charity no. 287475

PRENATAL SUPPORT Information for parents



 **Evelina Children's
Heart Organisation**

ECHO is here to support children with congenital heart defects who receive treatment at the Evelina Childrens Hospital , and to extend a lifeline to their family & carers. We are here to provide information, friendship and moral support prenatally, and from infancy to adulthood, especially at times of high anxiety for the patient and/or his or her family/carers. Our advocacy provides vital patient voice to help Guy's & St Thomas 's NHS Trust shape its services for congenital heart disease.

When you are first told that your unborn baby has a heart problem, you may feel shocked, upset and alone. Many parents who have been through a similar experience recall the day of diagnosis as one of the worst days of their life, as their dreams of a healthy baby seem to have been dashed. At this time you are also likely to be faced with unfamiliar words and terms, and it can be difficult to imagine what treatment lies ahead for your baby after birth.

Congenital heart disease (meaning to be born with) covers a wide spectrum of conditions and severity. Some conditions will be mild and may not need any treatment. Others can be corrected with surgery or other procedures, for example, cardiac catheterisation. More serious conditions may require a series of operations, but will still not correct the heart back to normal. However in all cases parents are likely to feel anxious and worried about the future.

Whilst the highly-skilled team of doctors, nurses and counsellors at the Evelina Children's Hospital can provide excellent care and support, we have found that being able to speak to other parents, who have already experienced a similar situation with their own child can really make a huge difference.

ECHO is a support group run by parents of "heart children" cared for at the Evelina. They are able to empathise with everything the newly diagnosed family are going through, and offer comfort and reassurance at this stressful time. This has led the organisation to develop prenatal support for parents. We can offer

- Telephone support from one of our trained prenatal support volunteers
- Signposting to sources of information or other relevant support groups.
- ECHO sponsored specialised antenatal classes for parents of heart babies who will be treated at the Evelina Children's Hospital. (Details will be given to you by the fetal cardiology dept. or your midwife).

"In April my husband, Matt, and I attended the Prenatal day with the Tower Midwife team at St Thomas' and were relieved to discover we were not the only parents of a heart baby. The course was a full day of valuable information and included a tour of the hospital; birth suite, neonatal intensive care, special care etc. We were told how we would be induced, how the baby would be transported and every question we had was answered. I thoroughly recommend the day to any expectant parent of a heart baby. We also heard from an experienced ECHO parent about her son and his surgery. As she described her feelings and fears when they first discovered his heart condition I thought I was going to burst into tears - it brought back all the feelings I had experienced and was still experiencing. I could relate to her immediately."

Joanna

"The level of support and the kindness we have received from ECHO and fellow members has been invaluable and no doubt we will call on them further in the next 12 months! For now though we are excited about our baby's impending arrival and I know for sure we wouldn't be feeling as positive or as excited if we hadn't received the support/info from ECHO. We are extremely grateful." **Jane**

"By the time Leo was due, we felt we had a whole other 'family' waiting for the good news!" **Pippa**

"The ECHO-sponsored parenting classes help prospective parents meet others who are in a similar situation and it always re-enforces that these classes are so vital when I always hear a parent-to-be saying " I am so pleased to meet everyone here, we now know we are not alone, we don't feel isolated or guilty that we have made the important decision to continue the pregnancy"

Manjit Randhawa - Matron - High Risk Teams (Thames and Tower Midwifery Teams)



**Don't be alone at this time -
contact ECHO and let us support you**

To speak to a Prenatal Support volunteer or for more information, please call **07943 625031** or email prenatalsupport@echo-evelina.org.uk