

## Useful information for parents when an anomaly has been diagnosed in their baby

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We have written this leaflet to give you some useful contacts if you wish to obtain more information.

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All the staff involved in scanning your baby realise what a difficult and stressful time this is for you. It can be difficult to retain information and remember what has been said during a consultation, so it is always a good idea to make a note of any questions as they come to you, and bring them with you to your next appointment. We will always do our best to answer them for you, but sometimes we will need to send you to another hospital for more scans and further tests before we can be completely sure of the answers. You can phone either of the screening midwives for more information between 8.30am and 4.00pm Monday to Friday. We are Annette Shore on 0118 322 8507 and Jo Young on 0118 322 7292.

Below are links to information that we have looked at and that other parents have found valuable:

- Antenatal Results and Choices offer information and support to parents who are making decisions before, during and after tests in pregnancy, either via the website at <http://www.arc-uk.org> or by phoning 0845 077 2290
- SHINE is a charity that provides information and support on Spina Bifida and related conditions, formerly known as ASBAH. Contact them on 01733 555988 or at <http://www.shinecharity.org.uk>
- The British Heart Foundation has produced a series of 7 different leaflets covering specific problems. Go to <http://www.bhf.org.uk/publications> and search for “Understanding Your Child’s Heart”. There is also a DVD which aims to answer your questions and offer practical support and advice
- CLAPA are the Cleft lip and Palate Association at <http://www.clapa.com>
- Contact A Family runs an online linking service to enable parents to meet others affected by the same condition at <http://www.cafamily.org.uk> or by phoning the free helpline on 0808 808 3555
- GEEPS: Gastroschisis Exomphalos Extrophies Parents Support is an international network of families of children born with abdominal wall defects. They provide clear information on conditions and their treatment at <http://www.geeps.co.uk>

- The Harris Birthright Centre is the research arm of the Fetal Medicine Foundation at King's College Hospital, London. They produce information on a range of problems including Twin To Twin transfusion Syndrome (TTTS) and Talipes at <http://www.harris-birthright.org>

If you have any problems accessing these sites or the information on them just ask one of the screening midwives to print the information for you.

### Further information

Leaflets for the following conditions can be accessed on the NHS Fetal Anomaly Screening Programme website

<https://www.gov.uk/government/collections/fetal-anomalies-screening-conditions-diagnosis-treatment>

- [Alobar Holoprosencephaly](#)
- [Anencephaly](#)
- [Bilateral renal agenesis](#)
- [Cleft lip](#)
- [Congenital diaphragmatic hernia \(CDH\)](#)
- [Congenital heart disease](#)
- [Exomphalos \(omphalocele\) Gastroschisis](#)
- [Lethal skeletal dysplasia](#)
- [Open spina bifida](#)
- [Trisomy 13 \(also called Patau's syndrome or T13\)](#)
- [Trisomy 18 \(also called Edward's syndrome\)](#)

This leaflet can be made available in other languages and formats upon request.

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