



**Royal Berkshire**  
NHS Foundation Trust

# **Where to get information after your baby has an anomaly diagnosed**

## Information for parents

Compassionate

Aspirational

Resourceful

Excellent

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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 time this may be 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 clearer of the information we need to give you. You can phone the screening midwives for more information, further emotional support or to change an appointment between 8.30am and 4.00pm Monday to Friday, available on 0118322 8507 / 7292 or 07768 752563.

## **National Screening Programme 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:](https://www.gov.uk/government/collections/fetal-anomalies-screening-conditions-diagnosis-treatment)

- Bilateral renal agenesis
- Cleft lip
- Congenital diaphragmatic hernia (CDH)
- Congenital heart disease
- Lethal skeletal dysplasia
- Neural Tube defects
- Trisomy 13 (also called Patau's syndrome or T13)
- Trisomy 18 (also called Edward's syndrome)
- Diagnostic tests

## Further information

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 by telephone on 01733 555 988 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.
- For help and support during pregnancy and after for babies with cleft lip, visit [www.spirecentre.nhs.uk](http://www.spirecentre.nhs.uk)
- For multiple pregnancy support or understanding their complications, you can visit [www.twintrust.org](http://www.twintrust.org) or call their helpline on 0800 138 0509.
- 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, please ask one of the screening midwives who will be happy to print the information for you.

To find out more about our Trust visit [www.royalberkshire.nhs.uk](http://www.royalberkshire.nhs.uk)

**Please ask if you need this information in another language or format.**

AN Screening Midwives, July 2009

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