Congenital Heart Disease
Information for parents
Information to help you understand more about Congenital Heart Disease.

This information sheet is designed to provide only an overview of the screening and diagnosis of congenital heart disease. For further detailed information please see the listed support groups or discuss this with your health professional.

1. What is Congenital Heart Disease (CHD)?

Congenital Heart Disease (CHD) refers to abnormalities of the heart that occur before a baby is born. There are three main types of heart problem which can occur: problems with the structure of the baby’s heart, problems with the heart function and problems with the heart rhythm. Abnormalities can range from small to much larger and more severe defects.

The NHS fetal anomaly screening programme has defined major congenital heart disease as any heart abnormality which requires medical attention immediately after birth or surgery within the first year of a baby’s life.

There is no single cause for congenital heart disease and often we do not know why it occurs. In some cases there can be problems with the baby’s chromosomes or genes but usually the abnormality occurs because something has gone wrong in the early development of the baby.

2. How common is it?

Major Congenital Heart Disease occurs in about 35 of every 10,000 births.

3. How is it diagnosed?

If a baby has a major congenital heart condition it would usually be seen during the Fetal Anomaly ultrasound scan carried out between 18 weeks and 21 weeks of pregnancy.

This scan looks for heart abnormalities which mean a baby will need medical attention very soon after birth or surgery within the first year of the baby’s life. Not all heart abnormalities can be seen before the baby is born.

Congenital Heart Disease can sometimes be detected during a scan earlier in pregnancy.

4. How is it confirmed?

A second scan, carried out by a specialist, will be needed to confirm the diagnosis.

Congenital Heart Disease is usually confirmed following referral to a specialist in fetal medicine and a fetal cardiologist (heart specialist). This will involve further scans to confirm the diagnosis and check whether your baby has other conditions. Once a diagnosis is made, the cardiologist and fetal medicine specialist will then be able to provide information about the abnormality, the treatment and the outlook for the baby. For some conditions the outlook is very uncertain.
5. What happens next?

If your sonographer (the health professional carrying out your scan) thinks there may be a problem with your baby’s heart you will be referred to a specialist for further scans and tests.

6. Further information, charities and support organisations

**Antenatal Results and Choices (ARC)**
Email: info@arc-uk.org
Helpline: 0845 077 2290
Website: www.arc-uk.org

Antenatal Results and Choices (ARC) provides information and support to parents before, during and after antenatal screening and diagnostic tests, especially those parents making difficult decisions about testing, or about continuing or ending a pregnancy after a diagnosis. ARC offers ongoing support whatever decisions are made.

**British Heart Foundation**
Phone: 0207 554 0000
Email: supporterservices@bhf.org.uk
British Heart Foundation Heart HelpLine
For information and support on anything heart-related: 0300 330 3311 (a similar cost to 01 and 02 numbers)
Genetic Information Service: 0300 456 8383 (a similar cost to 01 and 02 numbers)
Website: www.bhf.org.uk

The British Heart Foundation (BHF) is the nation’s heart charity, dedicated to saving lives through pioneering research, patient care, campaigning for change, and providing vital information.

**Children’s Heart Federation**
Freephone Infoline: 0808 808 5000 (9.30am - 4.30pm Mon to Fri)
Office phone: 0207 422 0630 (9am -5pm Mon to Fri)
Fax: 0207 247 2087
Website: www.childrens-heart-fed.org

Provides a range of information about all aspects of bringing up children with heart conditions, from coping with siblings to understanding heart conditions and their treatments.
This information has been produced on behalf of the NHS Fetal Anomaly Screening Programme for the NHS in England. In other countries, check with a health professional to find out whether there are any differences in approaches to screening.

All of our publications can be found online at www.fetalanomaly.screening.nhs.uk.

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