What causes congenital heart conditions?

The aim of this fact sheet is to provide you with information on what causes congenital heart conditions.

When do congenital heart conditions develop?

The heart is the first organ to function in the embryo. It develops between the 3rd and 10th week of pregnancy so most congenital heart conditions are present before the woman knows that she is pregnant.

What causes heart conditions?

In many cases the cause of congenital heart disease is unknown. There is a genetic instruction manual for heart development. We think that most congenital heart conditions result from a change in one or more of these genetic instructions (genes). There are also factors in the environment in which the baby develops and probably gene-environment interactions.

The following factors increase the probability of having a baby with a heart condition:

- diabetes and viral infections such as rubella (German measles) during pregnancy;
- a family history of congenital heart disease
- some chromosomal disorders, for example people with Downs Syndrome who have an extra chromosome 21 and people with Di George Syndrome who have a small deletion of chromosome 22 often also have a congenital heart condition.
- Alcohol in pregnancy and some recreational drugs. Some prescribed medications such as retinoids which are a treatment for acne.

.

However, the vast majority of heart conditions result from factors that are beyond the control of parents.

A family history

Every baby has approximately a 1 in 133 chance of being affected by congenital heart disease.

If you, your partner, one of your children, or your blood relatives have a congenital heart condition, then you have a family history of congenital heart disease.

If you have a family history of congenital heart disease, the risk of having a baby with a heart condition is increased to around 1 in 30 chance, higher if more than one relative or parent is affected.

Planning pregnancies

If there is a history of congenital heart disease in your family, then you should inform your doctor before planning a pregnancy. You, or your partner if you are male, should start folate supplements before becoming pregnant.

You may be referred for genetic counselling and if a genetic cause for the heart condition is identified you may be offered additional genetic tests in the pregnancy.

During pregnancy, you can ask to have an early fetal echo (a special ultrasound scan) at about 14 weeks. You will also have a full anomaly scan at around 20 weeks.

Caring for children with heart conditions

Information sheet

Moving on

Parents often experience emotions, such as anger, grief and denial on learning of a diagnosis. In particular, many parents want to know why their child has been born with a heart condition and it can be difficult to accept that they may not be able to find out.

Children's Heart Federation can put you in touch with other parents who know what it is like to have a child with a heart condition. We can also offer information, advice and support for heart children and their families.

Call our helpline for more information 0300 561 0065, or visit our website www.chfed.org.uk.

Glossary

Chromosome - Chromosomes are long pieces of the chemical named DNA which are found in the centre (nucleus) of cells. In a normal cell there are 23 pairs of chromosomes.

Gene – a genetic instruction in the DNA

Syndrome - A recognizable pattern that characterizes a specific disease or condition.

Evidence and sources of information for this CHF information sheet can be obtained at:

(1) National Institute for Health & Care Excellence. Structural Heart Defects Overview. London: NICE; 2017. Available at: https://pathways.nice.org.uk/pathways/structural-heart-defects

About this document:
Published: June 2015
Reviewed: May 2022

To inform CHF of a comment or suggestion, please contact us via info@chfed.org.uk or Tel: 0300 561 0065.

Caring for children with heart conditions

Information sheet