



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 develop in the embryo between the 6th and 12th week of pregnancy. It is at this time that defects can occur in the heart.

What causes heart conditions?

Most congenital heart conditions are 'genetic'. That is, the heart condition develops because of a mistake in the baby's genes.

It is still unclear why these mistakes occur. However, it is thought that certain factors may increase the risk of having a baby with a heart condition, including:

- rubella (German measles), diabetes and viral infections during pregnancy;
- a family history of congenital heart disease – if either parent or a brother or sister has a congenital heart condition, this may increase the risk; and
- some chromosomal disorders, for example, people with Downs Syndrome and Di George Syndrome often also have a congenital heart condition. Finding out your child has a heart condition can be very upsetting. It can be hard to take in everything you are being told. If you think of more questions after your appointment, book another appointment with the cardiologist or ask to speak to them on the phone.

Some research has suggested that drinking alcohol or taking drugs during pregnancy also increases the risk. However, the vast majority of heart conditions are the result of factors that are beyond the control of parents.

A family history

Every pregnancy has 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 a 1 in 25 chance. This rises to a 1 in 10 chance, 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 may receive pre-conception genetic counselling. Sometimes parents can also be tested to see if they carry the genes that cause a condition.

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.

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 **0808 808 5000**, or visit our **website www.chfed.org.uk**.

Glossary

Gene – A gene is a short piece of DNA, which tells the body how to build a specific protein. There are approximately 30,000 genes in each cell of the human body. The combination of all genes makes up the blueprint for the human body and its functions.

Chromosome – Chromosomes are long pieces of DNA found in the center (nucleus) of cells. DNA is the material that holds genes.

Syndrome – A collection of symptoms that characterize a specific disease or condition.