



HeartKids

Congenital heart disease: Causes

Information about the causes of congenital heart disease.



What is congenital heart disease?

Congenital heart disease (CHD) is a general term for a range of conditions that affect the way the heart works.

Congenital means the condition is present from birth. Congenital heart defects are the most common type of birth defect. 1 in 100 babies are born with a heart defect.¹

IN **8 OUT OF 10**
CASES OF CONGENITAL
HEART DISEASE



THERE IS **NO KNOWN CAUSE**²

What causes congenital heart disease?

In approximately 80% of cases of CHD, the cause is unknown.

Some mothers of babies born with CHD look critically at their own behaviours during pregnancy to try to find a cause for their child's illness. It is important to remember that most cases of CHD have no known cause.

Some of the known causes of CHD are:

- **Genes.** 20% of cases have a genetic cause.²
- **Illness during pregnancy.** Illnesses such as German measles can increase the risk of CHD.
- **Medications.** Certain medications can increase a mother's risk of having a baby with CHD if taken during pregnancy.
- **Age.** Babies of older women are more likely to have a birth defect than babies of younger women.

- **Other birth defects.** A baby with Down Syndrome is more likely to have a heart defect.
- **Smoking, drinking or taking drugs during pregnancy.**
- **Diabetes or poor nutrition during pregnancy.**

Will it happen again in our family?

Approximately 1% of babies are born with CHD.¹ The risk that it will happen again in your family varies depending on your situation and the condition.

We know that:

- If you already have a baby with CHD but have no other history of CHD in your family, your risk of having another baby with CHD increases slightly to around 3 – 4%
- If more than one sibling has CHD, the risk of having another child with CHD increases
- The risk of having a baby with CHD increases if one of the parents has CHD. If the mother is the affected parent, the risk that CHD passes on to the children is higher²

If you have CHD and are thinking of starting a family, you might have questions for your doctor about genetic testing. They can provide advice about your situation and a referral to a genetic counselling service if appropriate.



In most cases the cause is unknown, which can limit options for genetic testing.

What is genetic counselling?

Genetic counselling services provide information for people and families who have, or at risk of developing, certain birth defects.

If genes caused the CHD and doctors can identify which ones, it is easier to predict how likely it is that it will occur in another family member or child.

In some cases, they can provide detailed information about possible causes and the risks of a defect occurring again.

Talk to your doctor about genetic counselling and if it would be a good option for you.

References

¹ VAN DER LINDE, D., KONINGS, E., SLAGER, M., WITSENBURG, M., HELBING, W., TAKKENBERG, and J. J. & ROOS-HESELINK (2011). "Birth prevalence of congenital heart disease world-wide: a systematic review and meta-analysis." *Journal of the American College of Cardiology*. 58: 2241-2247.

² BLUE, G. M., KIRK, E. P., SHOLLER, G. P., HARVEY, R. P. & WINLAW, D. S. (2012). "Winlaw DS. Congenital heart disease: current knowledge about causes and inheritance." *The Medical Journal of Australia* 197: 155- 159.

This fact sheet was reviewed and updated by HeartKids in March 2021. It was endorsed by our Clinical Advisory Committee at the time of publication. Clinical information might change after this date. The information in this fact sheet is general. It is not a substitute for medical advice from your doctor. Always talk to your doctor about matters that affect your health.

Where to find more information and support

HeartKids

 heartkids.org.au

Learn more about CHD and the support HeartKids can offer you.

 1800 432 785

Call the HeartKids Helpline for support, advice and guidance.

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