

Frequently asked questions (FAQs)

How much blood will be required?

We will need 2mls or ½ a teaspoon of blood from newborns to two years of age, 5mls or a teaspoon from children up to eight years old and 9mls from older children and adults.

Are there any risks to my child in this procedure?

There are no known risks in giving this volume of blood. The blood is taken at the time of surgery when your child is anaesthetised.

Can I take my DNA out of the bank?

Yes, you can choose at anytime to request the sample be removed from storage by sending us a written request and all records as well as the sample will be permanently destroyed.

Can I or my child be cloned from the DNA sample stored?

It is not possible to clone individuals from DNA alone. Furthermore scientific and government regulation prevents human cloning.

Is there a benefit for me or my child?

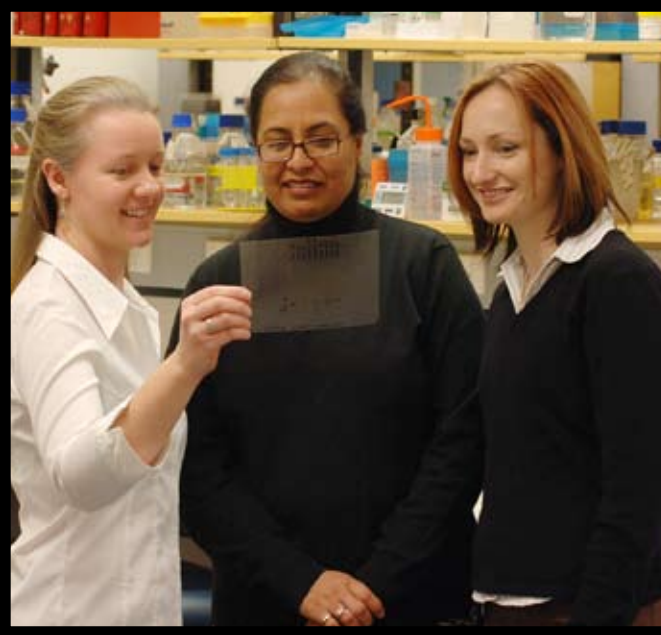
Although there is no immediate personal gain though being involved, you will be helping research to identify the causes of CHD. This is likely to help develop better treatments and preventative measures.

What if you find something important in the genes?

When you agree to be involved, you can choose to be informed of discoveries relevant to you, your child or their potential offspring. If you choose to be notified, this information will be passed to your cardiologist who will discuss it with you, or arrange for this to be done.

Further information please contact:

Kids Heart Research
Kidsheart@chw.edu.au
www.chw.edu.au/research/groups/khr.htm
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kids
heart research 
beating heart disease in kids

Kids Heart Research DNA Bank

*An initiative to help
understand the cause of
congenital heart disease*



The University of Sydney

Kids Heart Research DNA Bank

An initiative to help understand the cause of congenital heart disease

What is Congenital Heart Disease?

One in 100 children are born with a heart condition and diagnosed with 'congenital heart disease' (CHD).

Congenital heart conditions include holes in the wall of the heart, abnormalities of heart valves, defects of vessels such as the aorta and pulmonary artery or combinations of these.

CHD accounts for a high proportion of infants who require hospitalisation, operations and treatment in an intensive care.

Why do we need a DNA bank?

We do not know the cause of congenital heart disease. Research into the cause of CHD involves study of the genetic code, contained within the DNA.

Finding links between genes and heart disease require DNA from large numbers of affected individuals. By 'banking' DNA we will be able to accelerate research in this area. Although in some rare cases single gene or chromosome problems have been identified. Studies have shown a link between certain genetic changes and some forms of CHD in mouse models.

We are working with several other groups in Australia and around the world to identify the changes in human genes and their relationship to CHD.

Who can participate in the study?

All people affected by CHD and in some cases their parents and families are invited to donate. We also need the participation of unrelated people without CHD for comparative studies.

What will the study involve?

When you come into Hospital for preadmission clinic, you will be contacted by a genetic counsellor or clinical researcher who will discuss the study with you.

If you agree to participate we will collect a small blood sample from your child when they are asleep and under anaesthetic for the planned procedure. No additional needles are required. From the blood, we will extract DNA, which contains the genetic code.

At all times you will be free to ask questions regarding the study. Your treatment at the hospital will not be affected by whether you choose to participate in the study or not.

Who will have access to my DNA?

The DNA and clinical information is stored in a confidential and secure database accessible only to the manager of the DNA bank. The information and DNA can only be used by the Children's Hospital investigators or their colleagues working in the area of CHD and child health.

All samples have name and other identifying information removed and the samples are numbered to protect the privacy of your family and child. Laboratory workers are not able to 'see' the clinical information.

All studies and sample storage are approved by the Ethics committee of the Children's Hospital at Westmead and comply with the Privacy & Personal Information Act, and the Health Information Privacy Act.

