

## Frequently asked questions

### How much blood is required?

0 - 2 years: 2ml or ½ teaspoon

3 - 12 years: 5 mls or 1 teaspoon

12 or older: 9 mls or 2 teaspoons

### Are there any risks to my child in this procedure?

There are no known risks associated with collecting the volume of blood. The blood is collected at the time of surgery while your child is under anaesthetic or while your child is undergoing other clinical treatment.

### Can I take my DNA out of the BioBank?

Yes, you can request the sample be removed at any time by filling out a withdrawal of consent form. Your DNA and all records will be permanently destroyed.

### Is there a benefit for my child or I?

Although there is no immediate benefit from participating, you will be helping us identify the causes of childhood heart disease. This may help develop better treatments, outcomes and preventative measures.

### What if you find something important in my/my child's genes?

You can choose to be informed of results and findings relevant to you or your child. If you choose to be notified, this information will be discussed with you and your doctor. You will have access to a genetic counsellor who can assist with this and any questions you have.

### How long will my/my child's DNA sample be stored for?

DNA samples are stored indefinitely and are used in studies associated with childhood heart disease until the sample is used up. When your child turns 18, we will contact them to confirm that they wish to continue their participation now that they are an adult.



## For further information

### Kids Heart BioBank

Visit [www.heartcentreforchildren.com.au](http://www.heartcentreforchildren.com.au)

Phone: 02 9845 1333

Fax: 02 9845 2163

Email:

[SCHN-CHW-HCFCGeneticsService@health.nsw.gov.au](mailto:SCHN-CHW-HCFCGeneticsService@health.nsw.gov.au)

### Proudly incorporating Kids Heart Research and the Heart Centre for Children



The Sydney  
children's  
Hospitals Network

### Kids Heart Research

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Locked Bag 4001 Westmead NSW 2145

[www.kidsresearch.org.au](http://www.kidsresearch.org.au)



kids  
heart  
research



# Kids Heart BioBank

An initiative to understand the causes  
and outcomes of childhood heart disease



## What is childhood heart disease?

Childhood heart disease is a broad term for heart problems in children.

This includes congenital heart disease (such as holes in the heart), which may be present at birth. It also includes disorders of heart rhythm (such as long QT syndrome) or heart muscle (such as cardiomyopathy), which may develop later in childhood.

Some children with heart disease may require hospitalisation, heart surgery and treatment in an intensive care environment.

### Why do we need a BioBank?

We do not know the cause of most childhood heart disease. Research suggests that both genetic and environmental factors are involved. To study the genetic factors involved we need to access the genetic code, contained within our DNA.

Finding links between changes in our DNA and heart disease requires DNA from many patients. By collecting DNA, we will accelerate research into the causes and cures for childhood heart disease.

We are working with several other groups in Australia and around the world to identify the changes in our DNA and how they contribute to childhood heart disease.



### Who can participate in the study?

All children affected by heart disease and their families, are invited to participate. In some cases, we also ask healthy, unrelated people to participate for comparative studies.



### What will the study involve?

When you visit the hospital for treatment, 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 painlessly collect a small blood sample from your child while they are under anaesthetic for heart surgery or during other clinical treatment. From their blood we will extract their DNA, which contains the genetic code. This will be stored in the Kids Heart BioBank for current and future research into childhood heart disease.

Participating in this study is voluntary and 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?

DNA and clinical information is stored in a secure database, accessible only to the Kids Heart BioBank clinical research staff. The information and DNA can only be used by the study investigators of ethically approved research relating to childhood heart disease.

All DNA samples are de-identified and are given a unique code to protect the privacy of your child and family. Laboratory researchers are not able to access the identifying or clinical information.

All study processes are approved by the Sydney Children's Hospitals Network Human Research Ethics Committee and comply with current versions of the National Statement on Ethical Conduct in Human Research and the Health Records and Information Privacy Act.

