

## **SUPPLEMENTARY MATERIAL**

**Supplementary Data S1 – Detailed outline of brochure content**

# Congenital Heart Disease – How and why did this happen?

## **What is congenital heart disease?**

Congenital heart disease (CHD) is any problem with the child's heart that is present at birth. CHD affects about 1 in every 100 babies born.

In Australia more than 2,400 babies are born with CHD each year.

There are many kinds of CHD, some are minor and do not require any treatment, while others require treatment such as surgery.

[PICTOGRAM OF CHD INCIDENCE]

## **Causes of CHD**

For every 100 children who are born with CHD the cause is known or can be worked out for about 20.

[PICTORGRAM OF CHD CAUSES]

## **Known causes of CHD**

There are two types of causes: genetic and non-genetic.

### **Genetic causes of CHD**

In some cases a problem with the child's genes has led to the heart condition.

We all have about 20,000 genes in the cells of our bodies. Some of these genes are important for how our heart develops and works.

The genes are organized into strings of genes called chromosomes. We all usually have 46 chromosomes that are in pairs. So we have two copies of each of the 23 chromosomes. We inherit one copy from our Mum and one from our Dad. A problem with one or more of these genes can cause a genetic condition.

### Genetic conditions

Sometimes the gene problems can cause a "genetic syndrome". In these cases more than just the heart can be affected.

These syndromes can occur due to being born with:

- Extra copies of one of the chromosomes,
- A change in sections of one of the chromosomes, or
- A variation that has made one of the 20,000 genes that are important for the heart become faulty.

More rarely, CHD is not part of a genetic syndrome and is the only problem present. Changes affecting more than 30 different genes cause these forms of CHD.

If a genetic cause for the heart condition is suspected, parents may be referred to a Genetics Service, where more information about the condition as well as the possible genetic testing options can be discussed.

### **Non-genetic causes of CHD**

In rare cases, other factors, such as environmental factors, may have caused the CHD. We still do not understand the role of these factors in causing CHD.

Research is continuing but these basic recommendations may help to reduce the risk of a heart condition developing and should be considered before you fall pregnant:

- Talking to a doctor about any medications you plan to take during pregnancy
- Seeking advice such as taking a multivitamin containing folic acid before and during pregnancy
- Completing rubella (German measles) vaccinations
- Managing health conditions, such as diabetes, as well as possible

### **Unknown causes of CHD**

For every 100 children with CHD, the exact cause is unknown in 80 of them

Recent research suggests that in these cases, the heart condition most likely develops due to a combination of both genetic and environmental factors. So, rather than just one gene becoming faulty, variations in many genes involved in heart development may interact with each other and with environmental factors to cause CHD.

[PICTORGRAM OF GENETIC FACTORS + ENVIRONMENTAL FACTORS = CHD]

### **What are the chances that we will have another child with CHD?**

Most cases of CHD occur without a family history.

A genetic counsellor or genetic specialist can work out the specific chance for your family.

The table below is a general guide to working out that chance. These figures are worked out based on any other family member who have or had CHD.

[TABLE OF RECURRENCE RISK OF CHD]

### **More information and support:**

If you have any questions or would like more information about what is in this brochure, please contact:

- Heart Centre for Children Genetics Clinic [CONTACT DETAILS]

### **Additional information and support can also be found at:**

- Centre for Genetics Education [CONTACT DETAILS]
- Heart Centre for Children Psychology Service [CONTACT DETAILS]
- HeartKids Australia [CONTACT DETAILS]

**Supplementary Data S2 – Study pre- and post-questionnaires**

Participant ID \_\_\_\_\_

Date \_\_\_\_\_

## EVALUATION OF AN INFORMATION BROCHURE IN PARENTS OF CHILDREN WITH CONGENITAL HEART DISEASE (CHD)

### PRE-BROCHURE QUESTIONNAIRE

**Investigators:**

Once you have read the information sheet and signed the consent form, this is the **first** questionnaire to be completed **before** reading the brochure. We will use a unique number to link up your questionnaires so that you will remain completely anonymous.

If any of the questions or the brochure's content is distressing for you please don't feel that you have to continue, you can stop at any time and for any reason. Please inform a member of the research team and we will provide you with the contact details for the Heart Centre for Children Psychological Service.

If you have any questions about this questionnaire, please do not hesitate to contact....

A summary of the results of this study will be  
published on the Heart Centre for Children  
website...

**INFORMATION ABOUT YOU**

What is your age? \_\_\_\_\_ years

Are you male or female – please tick?  Male  Female

In which country were you born? \_\_\_\_\_

What language do you most often speak at home?  English Other: \_\_\_\_\_

What is your current marital status?  Never married  
 Married or de facto  
 Widowed  
 Separated or divorce  
 Other, please specify: \_\_\_\_\_

What is the highest level of education you have completed?  Year 10 or below  
 Year 12  
 TAFE certificate or diploma  
 Bachelor's degree at a University  
 Postgraduate degree  
 Other, please specify: \_\_\_\_\_

**INFORMATION ABOUT YOUR FAMILY**

How many children do you have? \_\_\_\_\_

What is the name of your child's heart condition? \_\_\_\_\_

How many surgeries has your child had? \_\_\_\_\_

Does your child have any other medical conditions? If yes please specify: \_\_\_\_\_

Apart from your child seeking treatment today, has anyone in your immediate family (i.e. parents, siblings, other children), or any of your close relatives (i.e. grandparents, uncles/aunts, grandchildren) had congenital heart disease? If yes, please write the relationship of this person(s) to you (e.g. mother, uncle), whether they are on the maternal or paternal side of your family and what the name of their CHD is:

Relative: \_\_\_\_\_  
Side of family: \_\_\_\_\_  
CHD type: \_\_\_\_\_  
Relative: \_\_\_\_\_  
Side of family: \_\_\_\_\_  
CHD type: \_\_\_\_\_

### What does the term 'congenital heart disease' mean?

*Congenital heart disease (CHD) is a heart problem that affects the structure and/or function of the heart. It is present from birth however may be detected a few years later.*

In this next section we would like to find **out how much you currently know about the causes and inheritance of CHD**. Please read each statement and circle either true, false or unsure according to what you think is correct.

A. CAUSES AND INHERITANCE OF CHD	TRUE	FALSE	UNSURE
1. CHD occurs in 1 in a 10,000 of babies born	T	F	U
2. The cause of the majority of CHD is still unknown	T	F	U
3. CHD can be caused by genetic factors	T	F	U
4. Most cases of CHD occur with a family history of heart disease	T	F	U
5. Diabetes, rubella (German measles) and certain drugs can increase the risk of CHD	T	F	U
6. CHD can be part of a genetic syndrome	T	F	U
7. Most cases of CHD are due to a combination of genetic and environmental factors	T	F	U
8. After having a child with CHD, the chance of having <u>another with CHD</u> is higher	T	F	U
9. The chances of having a child with CHD <u>is higher if the mother with CHD than if the father does?</u>	T	F	U
10. The risk of having another child with CHD can be up to 50% if it is a <u>known genetic cause</u>	T	F	U



In this next section we would like to find out **what information you have received on the causes and inheritance of CHD before today and how you have obtained this information.** We would also like to determine **whether receiving this information is important to you.**

B. INFORMATION ON CHD...	Yes	No	Unsure
1. I have received information on the possible <b>causes of CHD</b> from a medical professional	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>If you answered yes to the question above,</u> were you satisfied with the information you received?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I obtained information on the possible <b>causes of CHD</b> by my own research (i.e. via internet, books etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I would like more information on the possible <b>causes of CHD</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I think it is important for parents and family members to receive information on the possible <b>causes of CHD</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I have received information on the <b>inheritance and recurrence risks of CHD</b> from a medical professional	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>If you answered yes to the question above,</u> were you satisfied with the information you received?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I obtained information on the <b>inheritance and recurrence risks of CHD</b> by my own research (i.e. via internet, books etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I would like more information on the <b>inheritance and recurrence risks of CHD</b> for my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I think it is important for parents and family members to receive information on the possible <b>inheritance and recurrence risks of CHD</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

For the questions below we are interested in **the emotional aspects of having a child with CHD** and what can be done to better address your needs.

C. FEELINGS ABOUT CHD...	Yes	No	Unsure
1. I would like more support addressing my emotional concerns about how and why my child has CHD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I believe my child has CHD because: _____ _____			
3. I believe CHD is just something that 'happens' and is no one's fault	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I worry that my next child will also have CHD ( <i>if you are not planning any more children, hypothetically, do you think you would worry about your next child also having CHD</i> )	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Receiving more information on the possible causes and inheritance of CHD may help reduce my worries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I am unsure of what to say to my child when they ask how and why they have CHD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I would like more information on how I can explain the 'why' and 'how' of CHD to my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



Please read the following statements and indicate **the extent to which you agree with them** by ticking a box on the right.

D. I agree with this statement...	Completely agree	Somewhat agree	Do not agree
1. I think I understand why information on the causes and inheritance of CHD may be important for families with CHD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I have a good understanding of the possible genetic implications of CHD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I have a good understanding of what factors may have contributed to CHD	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I feel I have the tools to make decisions that will influence my child's future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I feel I can make a logical evaluation of the various options available to my child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I feel I can make decisions that will change my child's future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I feel there are certain things I can do to prepare myself should CHD reoccur in my family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I feel I know what to do to cope with the situation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I know where to go or who to ask should I need any more information or support relating to CHD.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Is there anything else you would like us to know?**

*\*If answering this questionnaire has raised any issues or concerns for you or if you would like any further information or support, please make a note of this here and we will contact you in regards to this*

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*Thank you for taking the time to participate in this study and helping us better understand your needs as parents of children with heart disease*

Participant ID \_\_\_\_\_

Date \_\_\_\_\_

## EVALUATION OF AN INFORMATION BROCHURE IN PARENTS OF CHILDREN WITH CONGENITAL HEART DISEASE (CHD)

### POST-BROCHURE QUESTIONNAIRE

**Investigators:**

Once you have read the information sheet and signed the consent form, this is the **second** questionnaire to be completed **after** reading the brochure. We will use a unique number to link up your questionnaires so that you will remain completely anonymous.

If any of the questions or the brochure's content is distressing for you please don't feel that you have to continue, you can stop at any time and for any reason. Please inform a member of the research team and we will provide you with the contact details for the Heart Centre for Children Psychological Service.

If you have any questions about this questionnaire, please do not hesitate to contact....

A summary of the results of this study will be  
published on the Heart Centre for Children  
website...

**What does the term 'congenital heart disease' mean?**

*Congenital heart disease (CHD) is a heart problem that affects the structure and/or function of the heart. It is present from birth however may be detected a few years later.*

In this section we would like to find if the genetic counselling session **has improved your understanding of the causes and inheritance of CHD**. Please read each statement and circle either true, false or unsure according to what you think is correct.

A. CAUSES AND INHERITANCE OF CHD	TRUE	FALSE	UNSURE
1. CHD occurs in 1 in a 10,000 of babies born	T	F	U
2. The cause of the majority of CHD is still unknown	T	F	U
3. CHD can be caused by genetic factors	T	F	U
4. Most cases of CHD occur with a family history of heart disease	T	F	U
5. Diabetes, rubella (German measles) and certain drugs can increase the risk of CHD	T	F	U
6. CHD can be part of a genetic syndrome	T	F	U
7. Most cases of CHD are due to a combination of genetic and environmental factors	T	F	U
8. After having a child with CHD, the chance of having <u>another child with CHD</u> is higher	T	F	U
9. The chances of having a child with CHD <u>is higher if the mother has CHD than if the father does?</u>	T	F	U
10. The risk of having another child with CHD can be up to 50% if there is a <u>known genetic cause</u>	T	F	U

Please read the following statements and indicate **the extent to which you agree with them** by ticking a box on the right.

B. I agree with this statement...	Completely agree	Somewhat agree	Do not agree
1. I think I understand why information on the causes and inheritance of CHD may be important for families with CHD.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I have a good understanding of the possible genetic implications of CHD.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I have a good understanding of what factors may have contributed to CHD.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I feel I have the tools to make decisions that will influence my child's future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I feel I can make a logical evaluation of the various options available to my child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I feel I can make decisions that will change my child's future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I feel there are certain things I can do to prepare myself should CHD reoccur in my family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I feel I know what to do to cope with the situation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I know where to go or who to ask should I need any more information or support relating to CHD.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

1. How long did it take you to read the brochure?

- <sub>1</sub> Less than five minutes
- <sub>2</sub> Between five and ten minutes
- <sub>3</sub> More than ten minutes

2. Since you read the brochure, how much have you thought about the information that was in it?

- <sub>1</sub> Not at all
- <sub>2</sub> A little
- <sub>3</sub> Somewhat
- <sub>4</sub> Quite a bit
- <sub>5</sub> A lot

3. Please indicate if you thought the brochure was:

	Very	Somewhat	Neither	Not very	Not at all
<b>Clearly presented</b>	1	2	3	4	5
<b>Informative</b>	1	2	3	4	5
<b>Easy to read</b>	1	2	3	4	5
<b>Useful</b>	1	2	3	4	5
<b>Appealing to look at</b>	1	2	3	4	5

4. Were there any parts of the brochure that you thought should have been explained in more detail?

- <sub>1</sub> Yes  
<sub>2</sub> No

If yes, what parts did you think needed more detail?

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5. In your opinion, was there anything in the brochure that was confusing?

- <sub>1</sub> Yes  
<sub>2</sub> No

If yes, what did you find confusing?

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6. How relevant do you think the information in the brochure is to you?

- <sub>1</sub> Not at all relevant  
<sub>2</sub> Not very relevant  
<sub>3</sub> Neither relevant nor irrelevant  
<sub>4</sub> Quite relevant  
<sub>5</sub> Very relevant

7. How clearly did the brochure explain your situation to you?

- <sub>1</sub> Very unclear  
<sub>2</sub> Unclear  
<sub>3</sub> Neither clearly nor unclear  
<sub>4</sub> Clearly  
<sub>5</sub> Very clearly

8. Did the brochure meet your expectations?

- <sub>1</sub> Not at all
- <sub>2</sub> I was a bit disappointed by the brochure
- <sub>3</sub> The brochure met my expectations
- <sub>4</sub> The brochure exceeded my expectations
- <sub>5</sub> The brochure greatly exceeded my expectations

9. How satisfied were you with the information in the brochure?

- <sub>1</sub> Very satisfied
- <sub>2</sub> Satisfied
- <sub>3</sub> Neither satisfied or dissatisfied
- <sub>4</sub> Dissatisfied
- <sub>5</sub> Very dissatisfied

10. Did reading the brochure make you feel worried or concerned?

- <sub>1</sub> Not at all
- <sub>2</sub> A little
- <sub>3</sub> Somewhat
- <sub>4</sub> Quite a bit
- <sub>5</sub> Very much so

What, if anything, made you worried?

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11. Did the brochure reassure you?

- <sub>1</sub> Not at all
- <sub>2</sub> A little
- <sub>3</sub> Somewhat
- <sub>4</sub> Quite a bit
- <sub>5</sub> Very much so

What, if anything, reassured you?

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12. Did reading the brochure make you feel upset or sad?

- <sub>1</sub> Not at all
- <sub>2</sub> A little
- <sub>3</sub> Somewhat
- <sub>4</sub> Quite a bit
- <sub>5</sub> Very much so

What, if anything, made you upset?

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13. Do you think the brochure will help you cope better with your situation?

- <sub>1</sub> Not at all
- <sub>2</sub> A little
- <sub>3</sub> Somewhat
- <sub>4</sub> Quite a bit
- <sub>5</sub> Very much so

What, if anything, would have helped you to cope better?

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14. What do you think are the main ideas that the brochure is trying to get across?

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15. What did you like best about the brochure?

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16. What did you like least about the brochure?

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17. Was there anything you wanted to know about the causes of congenital heart disease that wasn't covered in the brochure?

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18. Do you have any other suggestions about how the brochure could be improved?

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19. Would you recommend this brochure to other people who have children with congenital heart disease?

- <sub>1</sub> Yes I would.
- <sub>2</sub> I'm not sure.
- <sub>3</sub> No I would not.

If not, why not?

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**Is there anything else you would like us to know?**

*\*If answering this questionnaire has raised any issues or concerns for you or if you would like any further information or support, please make a note of this here and we will contact you in regards to this*

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*Thank you for taking the time to participate in this study and helping us better understand your needs as parents of children with heart disease*

