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## INFORMATION SHEET FOR MINORS (6-9)

# DOES IT MATTER IF MY HEART HAS AN UNUSUAL VALVE?

We are asking whether you and your family would like to take part in a research study.

Before you decide if you would like to join in, it is really important that you understand what the study is about, why the study is being done and what it will mean if you take part. So please read this leaflet carefully with your parents. Also talk to your family, friends, doctor or nurse about it if you want.

If something doesn't make sense or you have more questions you can ask your parents to give us a call and we can discuss it with you and your parents.

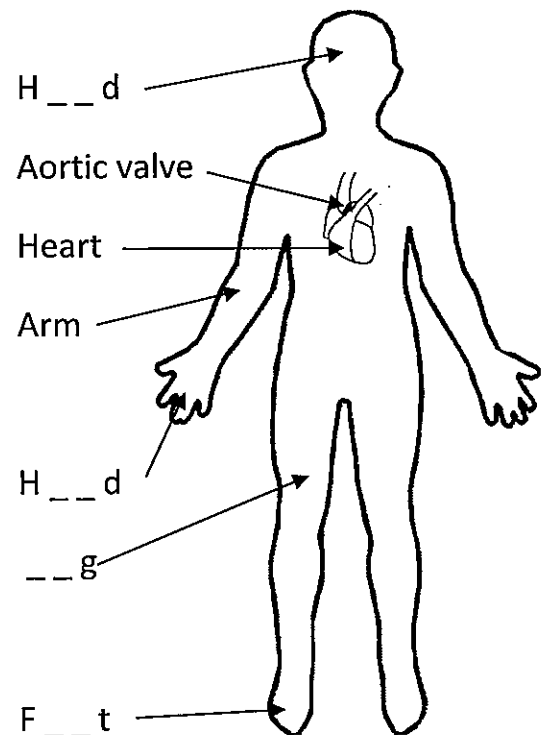
Thank you for reading this.

### INFORMATION SHEET

#### What is research? Why is this project being done?

Research is a way we try to find out the answers to questions.

This research is being done to look at one of the valves in your heart where the blood flows through.



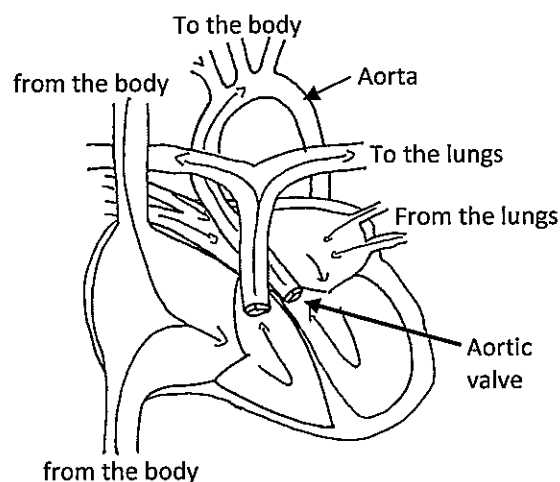
Can you fill in the missing letters?

Subject: Information sheet/BAV minors (6-9)  
Short Title: OXBAB  
Principle Investigator: Prof Stefan Neubauer

Version/Date: 1/27.09.2010  
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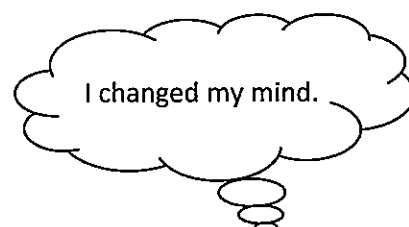
Your heart pumps blood all the way through your body. To make sure it all goes in the right direction the heart has 4 valves. In our research study we are looking at one of them, the aortic valve. Most people have a valve with 3 parts but in some people it only has 2 parts.

We also know that other people in the family can have a valve with two parts as well. That is why we are asking your family to take part in the study, too.



### Why have I been asked to take part?

You have been asked to take part because you or someone in your family has an unusual valve in your heart.



### Did anyone else check the study is OK to do?

Before any research is allowed to go ahead it has to be checked by a group of people to make sure that the research is fair.

### Do I have to take part?

No, you don't. It is your choice whether you want to take part and you can always change your mind.



### What will happen to me if I take part?

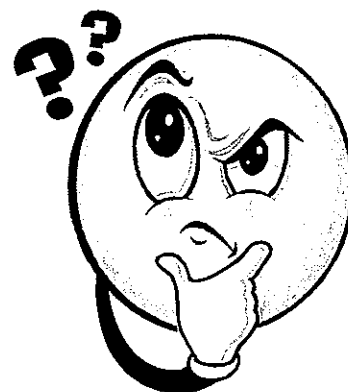
We have to ask you not to have any breakfast that morning. But you can drink water and we'll have breakfast for you during your visit.

Once we have checked that you and your parents are happy for you to take part we will invite you to the clinic in Oxford.



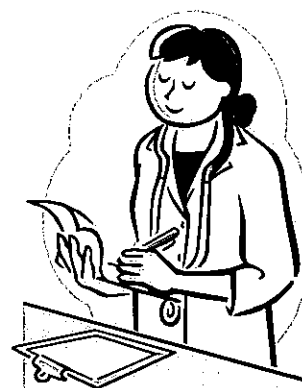
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Then you and your parents can ask any questions you have.

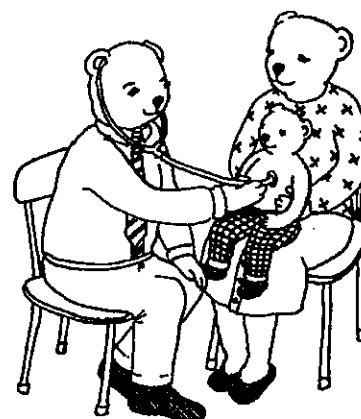


Then we will:

Ask your parents some questions.



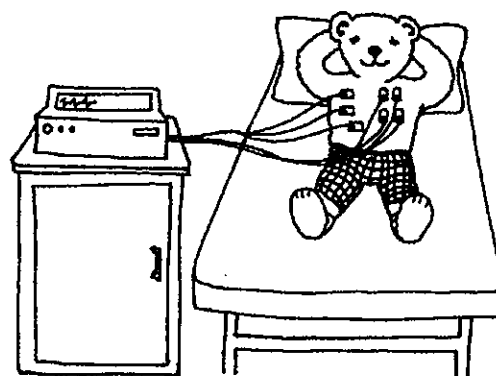
Measure how tall and how heavy you are, take your blood pressure and listen to your heart.



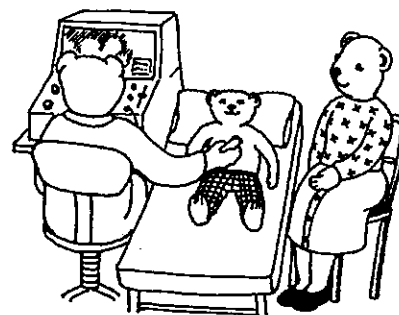
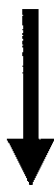
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Take a trace of your heart (ECG) where a machine draws squiggly lines of your heart on a piece of paper. This shows how well your heart is working.



Do a jelly scan (Ultrasound scan) of your heart and arm while you can find “where’s Wally”, Winnie the Pooh, Thomas, Nemo or Princesses if you want to.



Give you a certificate for taking part.



When you are older in a few years time we will also ask you to come back for another visit just like this one. This is to see whether anything changed.

### Will anything about the research upset me?

All measurements we choose are safe. The jelly scan might tickle a bit and during the heart trace you need to lie still. The blood pressure cuff will give your arm a gentle squeeze.

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### Will taking part help me?

The study will not help you right now. But it will help us to know more about people having an unusual valve in their heart.

### What happens when the research study stops?

The research will be talked about and written down but no one will know that you took part.

### What if something goes wrong?

If there is a problem you can talk to your parents or any of the researchers.

### Will my information be kept private? Will anyone else know that I am taking part?

All your information will be kept private. We will only tell your parents and your GP.

### What do I do if I don't want to take part in the research anymore?

Just tell your parents and the researchers that you don't want to take part anymore. You don't have to give any reason. It is **YOUR** choice.

### What happens if I find out that I have an unusual valve I did not know about?

Just like the person in your family (brother, sister, mum or dad) who already knows that they have an unusual valve in their heart you would see a heart doctor in outpatient clinic every few years.

Z D Y R M H E M I E Y S  
S X H B O P T R A E H A  
V A L V E T A V I R P J  
E Y C H O I C E Z M V E  
S P N H P L I O S E S L  
N P E C G W F R D A T L  
K A M A C H I N E S S Y  
L H S N O I T S E U Q S  
U I T Y N A R T J R D N  
M J W M T A E C N E E B  
R E S E A R C H E R P E  
L E G I G O O S B I F G

Find all 14 words hidden in the puzzle:

ECG	Valve
Heart	Choice
Researcher	Machine
Jelly	Questions
Private	Happy
Scan	Certificate
Doctor	Measure

I changed my mind.



Special thanks to the charity HeartLine and Sheila Barns for giving us permission to use the drawings from their leaflet "Growly Bill and the Outpatients Clinic".

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