



INVITATION TO TAKE PART IN A RESEARCH PROJECT TO IDENTIFY THE GENES THAT CAUSE INHERITED CONGENITAL HEART DISEASE

BACKGROUND

Heart development is a complex process and errors in normal development lead to congenital heart disease (CHD). Many genes are known to be involved in heart development but these cannot explain all the causes of CHD. Hence we would like to identify new genetic causes of CHD.

WHO WOULD BE SUITABLE TO PARTICIPATE?

We would like to hear from two types of families. Those with:

- A) Two or more children in the family with CHD (the affected children can be brothers or sisters or cousins), but their parents do not have CHD**
- B) One or more children in the family with CHD, and their parents are blood relatives (e.g. cousins)**

Such families could be very helpful for identifying more CHD genes.
(Of note we may extend our research to other families at a later stage).

DO YOU HAVE TO TAKE PART AND WHAT WOULD BE REQUIRED?

Taking part in the project is simple and entirely voluntary. If you are interested in taking part but change your mind then you can withdraw at any time. If you agree to take part we will ask you and other members of your family to provide a small blood sample (taken through a needle from a vein in your arm) and give permission for us to obtain medical details from your children's cardiology unit.

WILL THIS PROJECT BENEFIT YOUR FAMILY?

We cannot guarantee to discover anything that will directly benefit your family. However, if we identify a CHD gene that might be relevant to your family we will contact you (unless you ask us not to) to let you know what gene tests might be available. New gene tests would be helpful for identifying which families might be at risk of having further children with CHD and for improving our understanding of how the heart develops.

WHO DO YOU CONTACT FOR MORE DETAILS?

If you have any questions or concerns about this project, please contact one of the following:

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