

RESEARCH STUDY: Genetics of Left Ventricular Outflow Tract Malformations

If you or your child has been diagnosed with bicuspid aortic valve, aortic valve stenosis, mitral valve stenosis, coarctation of the aorta, interrupted aortic arch type A, Shone complex, or hypoplastic left heart syndrome, we would invite you to participate in a research study called “Genetics of Left Ventricular Outflow Tract Malformations”

What is the purpose of this study?

Through this study, we hope to understand how changes in genes might cause the heart defects listed above which together are called left ventricular outflow tract malformations. We need to study genetic differences between people who have heart defects and those who don't to find the causes of heart defects. Sometimes heart defects may be caused by a change in a single gene. Other times heart defects seem to be caused by a combination of genes and the environment. We hope by understanding genes that can cause heart defects we can then learn how to prevent these defects from happening in other children.

Who is doing this research?

This study is led by Dr. Kim McBride and is funded through the National Institutes of Health. The study coordinator for this study is Sara Fitzgerald-Butt.

How can my family participate?

Ideally, the individual with the heart defect and his/her biological parents would participate in this study. If one or both parents are not willing or not able to participate in the study, those who are willing can still participate.

Those who would like to participate should be willing to have their blood drawn (preferred) or give spit sample. Additionally, they should be willing to discuss how many relatives they have, their ages and if any of them have heart problems. Lastly, mothers of children with heart defects should also be willing to complete a phone interview about their pregnancy.

Are there any costs associated with participating?

It will not cost you anything to be in this study. For your time and effort, your family will receive a gift card.

How can I learn more?

If you have questions, would like more information or would like to be part of this study, please contact the study coordinator, **Sara Fitzgerald-Butt by telephone (614-355-3497) or email (Sara.Fitzgerald-Butt@NationwideChildrens.org).**

You may also complete the form below and return it by **fax (614-722-2817) or mail (Sara Fitzgerald-Butt, Wexner – Genetics, 700 Children's Dr., Columbus OH 43205).** The study coordinator will then contact you.

Name

Address

Daytime phone

Evening phone

