

Version 5, 20th June 2017

Genetics of Growth Hormone Insensitivity (GHI) (Primary IGF-1 Deficiency, PIGFD)

Information sheet for family members aged 6-12 yr

Research to find out why some people are small

What is this study?

Research is a way to find out answers to questions. We are doing research to try and find out why some people do not grow properly. We do this by looking at a person's genes to try and find any mistakes which might cause problems with their growth. We want to find out why some people are small. To do this, we would like you to let us to take a blood sample from you.

Why have I been asked to take part?

You have been asked to take part because someone in your family is small or they are not growing properly. This may be due to a condition called growth hormone insensitivity (GHI). Your blood sample will help us to see if there is something in the genes that is causing the problem in your family.

Do I have to take part?

No. It is up to you to decide whether or not to take part. You will be asked on another piece of paper if you would like to take part. You don't have to do this and you can change your mind at any time.

What will happen if I take part?

We will need to take one small sample of blood (this means having a needle prick to get the blood). Sometimes, we will ask for a small sample of your skin. To do this, your skin is cleaned and medicine is

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put on your skin to make it numb. When the skin is numb, a small circle of skin (less than a quarter the size of your little fingernail) is taken. You might see a little bit of bleeding but stitches are not usually needed. The plaster can be taken off after about 2 days. It is up to you to decide whether or not you would like to give us a skin sample and you can tell us if you want to or not.

How will joining in help?

The information we get might help treat young people who are small with better medicines in the future.

Will anyone else know I am doing this?

Only your parents, your family doctor and the people doing the research will know that you are taking part.

Did anyone else check the study is OK to do?

A group of people called the Ethics Committee have checked that the study is OK to do. We are also asking your parents permission.

Who can I contact to find out more about this study?

If you have any questions please contact the following:

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