

Version 5, 20th June 2017

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

Information sheet for patients 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 and we are doing a study to look at someone's genes that might cause problems with growth. We want to find out why you are small. 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 you are small or 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 your genes that is causing the problem in you.

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 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

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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?

We cannot promise the study will help you but 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, the doctor and nurses looking after you 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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