

CHILDREN'S INFORMATION SHEET (Age 10-15)

A STUDY OF PEOPLE WITH HEARING AND VISION PROBLEMS (Norrie Disease)

Version 2, 07 May 2024

We would like to ask you to be part of this study. Before you decide, your parent or another adult will read this information sheet to you. Please ask if something is not clear or if you want any more information.

Why is the study being done?

We want to learn more about what Norrie disease is, and how Norrie disease has affected you. It will be very helpful for us to find out more about you, even though we can't make your hearing or vision better straight away by doing this. By understanding what happens in each person though, and by doing our laboratory work as well, we will have a better chance of working towards helpful treatments the future.

Do you have to take part?

No you don't have to. It is up to you and your parents. You can change your mind at any time. If you are not happy with something please tell your parents.

If you do decide to take part:

- √ We will ask you to sign a form to say that you agree to take part (an assent form)

- √ We will give you this information sheet and a copy of your signed assent form to keep.

You are free to stop taking part at any time during the research without a reason. If you decide to stop, this will not affect the usual care you receive.

What happens if you take part?

- √ We will make a time to meet you and your family.
- √ We will ask you and your parents some questions about your eyes, ears and any other medical problems you may have had.
- √ We may need to look at your eyes, ears, face, legs and skin, but if we do, your parents can stay with you for this. This will take about 1 hour, and your parents will be with you the whole time.

Did anyone check that this study is OK to do?

Before we do any research, a group of people check to make sure that it is OK to do.

Will all my information be kept private?

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

We will talk about this research and write scientific articles, but nobody will be able to tell that you took part.

Contact for further information.

Please contact a member of the research team on the email addresses shown below for further information. Thank you for taking part in this study. This is your copy of the information sheet.

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