

Establishing a database as part of the European Reference Network on rare liver diseases (R-LIVER)

Dear,

Your doctors are treating you because you have a rare form of liver disease.

We are your doctors and we would like to save information about your disease. This includes for example, how fast you grow and how your blood test results change. This information should be saved along with information about children from other clinics and from other countries. This will let us learn how to better treat your disease in the future.

You and your parents can decide together if your information should be saved. Nobody is forcing you to take part. You can just say “no” if you like. You will be treated the same whether you say “yes” or “no”. Your treatment will not change.

There is no need to decide right now. Take a few days to think about it. Your parents will certainly be able to answer most of your questions and your doctor will be happy to talk about it with you. You can ask him/her all of your questions. He/she will answer you.

Can it get uncomfortable or can anything bad happen?

If you let us record the information about the disease such as blood test results, your medicine or your weight and put them together with the information of other children, nothing will change in your treatment. Your medicine and examinations will not be any different.

Does information about how your disease grows always have to be collected in the future?

Because it is your choice whether we are allowed to collect information on your blood test results, your weight, your height and your medicine, you can stop allowing us at any time. If you want to stop us, you do not need to give a reason. If you stop, your future treatment will be the same.

Who can you ask if you have questions?

If you have any more questions, you are welcome to ask us. We will be happy to answer your questions.

Do you want to take part? *(If applicable, only confirmation of doctor who explained)*

If you would like to take part, we ask that you sign this page. This tells us that we are allowed to collect information about your liver disease and that this is your decision. You can always change your mind later and tell us that you do not want to take part any more. Nothing bad will happen to you if you do.

I want information about my disease to be collected.

Name of child in block capitals

Place, Date

Signature of child

I have held the discussion with the child to explain the above. I am convinced that the child has understood, that he/she has no further questions, and that *he/she has not rejected taking part.*

Name of doctor who explained (block capitals)

Place, Date

Signature of doctor who explained