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INFORMATION LEAFLET FOR CHILDREN AGED 6-10

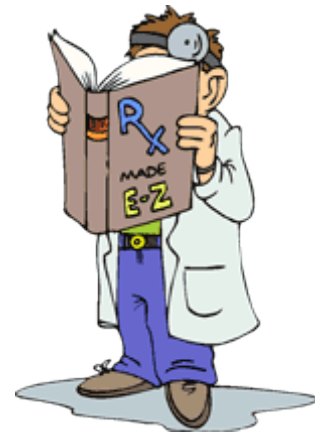
A research study to determine the genetic causes of PSC and childhood autoimmune liver disease

Version 2, 08.03.18

Part 1 Summary

We are asking you to take part in a research study. Research is when doctors ask questions to find answers to things they need to know more about. Before you decide if you would like to join in, it is really important that you understand what the study is about.

Please read this carefully or ask your parents or guardian to read this to you. There may be words you do not understand. Ask your doctor or nurse, parents or guardian if you do not understand something. You can also ask your parents or guardian to give us a call and we can discuss it with you. Thank you for reading this.



Part 2 More information

Here is some more information to help answer some of the questions you might have.

1. What is the study about?
2. Why me?
3. What will I have to do?
4. Do I have to join?
5. Where will I go to take part?
6. Will anyone know that I am taking part?
7. What if I change my mind?
8. What happens now?



Part 2

1. What is the study about?

This study is trying to find out why some children, like you, get autoimmune liver disease.

Sometimes grown-ups and children become unwell. The doctors and nurses who look after you and your family, work with scientists to learn more about different diseases and how they make us unwell. Genes are the building blocks of your body which make you unique and they store a lot of information important for keeping us healthy. Doctors and scientists are interested to find out how genes work and cause diseases and by doing so trying to stop people becoming unwell.

**2. Why me?**

We are asking you to take part because you have an autoimmune liver disease. We would like to find out more about these illnesses, as we do not know at the moment what causes them.

3. What will I have to do?

Your doctor will talk to you and your parents or guardian. If they are happy for you to join the study, we will ask you to give a small amount of blood (approximately 1 teaspoon). We will usually only take blood when you are already visiting your doctor and are having other blood taken. Your doctor or nurse will explain how this is done. We can put cream or spray on your arm so it does not hurt as much.



We will also ask your parents or guardian to answer some questions about your liver disease.

Your blood will be sent to our scientists and they will look at it. These researchers will include doctors and scientists. Blood samples are stored in a special freezer so we can use it for other projects but we would ask for your parents' or guardian's permission before we do so.

4. Do I have to join?

No, it is up to you and your parents or guardian to decide. It is ok if you do not want to take part and it will not change the way the doctors and nurses look after you. If you do not want to have the blood samples taken, your parents or guardian can agree to answer some questions about your liver disease which would be very helpful as well.

5. Where will I go to take part?

You can take part the next time you go to your hospital to see your doctor about your liver. This way you will not have to cancel any plans with your friends and you do not have to miss any school. You can take the questionnaire home for your parents or guardian to fill in. When they are finished, they can post it back to us.

6. Will anyone know that I am taking part?



The only people that will know you are taking part are your parents or guardian, and the doctors and nurses who are looking after you. We will give your blood samples a unique code, so that the scientists will not know your name or any other details about you.

7. What if I change my mind?

You can change your mind about taking part at any time and do not have to tell us why. Just let your parents or guardian and doctor know that you do not want to take part anymore.

8. What happens now?

If you decide 'yes' then you will have the chance to sign a form. Your parents or guardian will also have to sign a form. This means that they allow you to take part.

Thank you for reading this. If you have any questions please ask your doctor, nurse, parents or guardian.