



PARTICIPANT INFORMATION SHEET (YOUNG SIBLING) FOR CHILDREN 6 - 10YRS

Rare Diseases

Version 1 02/03/2015



Please read this. There may be words you do not understand. Ask your doctor or nurse or parents if you need help to read or understand this. Thank you for reading this.

Sometimes grown-ups and children become unwell. The doctors and nurses who look after your family, work with scientists to learn more about why and how we sometimes become unwell. The more we learn about how our bodies work, the more chance we have of stopping people becoming unwell in the future.

Why me?

We are asking boys and girls who have a brother or sister that are not well and often have to see a doctor or nurse.

What will I have to do?

Helping involves giving us a small amount of skin*, a blood sample, and sometimes some hairs plucked from your head, or a sample of wee. If you haven't given blood before then we can tell you how we do this. It will hurt a bit but we can put some cream or spray on your arm to make sure it doesn't hurt very much, and if you give skin, we will give you a small injection to numb the area.

****sometimes we can manage without taking a skin sample, we will talk about this with you and your parents***

Do I have to join?

No, taking part is up to you. It's ok if you don't want to take part.

What will happen next?

We may invite you to take part again in a different study. If you are invited we will give you and your family lots of information to help you understand how you can help. You won't have to take part if you don't want to.

Where will the study take place?

A doctor or a nurse might collect a sample the hospital your brother or sister visits the next time they go. Your mum / dad can stay with you whilst we collect the sample. We will try and make sure that we see you when it's best for you. We don't want to stop you going to school or catching up with your friends.

Will anyone else know I'm doing this?

No one else apart from your family, the doctors and nurses and key members of the research team will know you're taking part.

If you decide to help then your skin and blood will be given a special number. The scientists who will look at your skin/ blood will not know who you are.

What if I don't want to take part anymore?

It's ok if you decide to join the study and then change your mind. You can stop taking part at any time and you don't have to say why. You can still keep coming to the hospital to see the doctors and nurses for your regular care.

If I say 'yes' - what next?

If you say 'yes' then you will be asked to sign a form. Your mum or dad will also have to sign a form. This means that they allow you to take part.

Thank you for reading this - please ask any questions if you need to.