

BioResource for Rare Diseases

(part of the NIHR BioResource)

Children 6 - 10 years

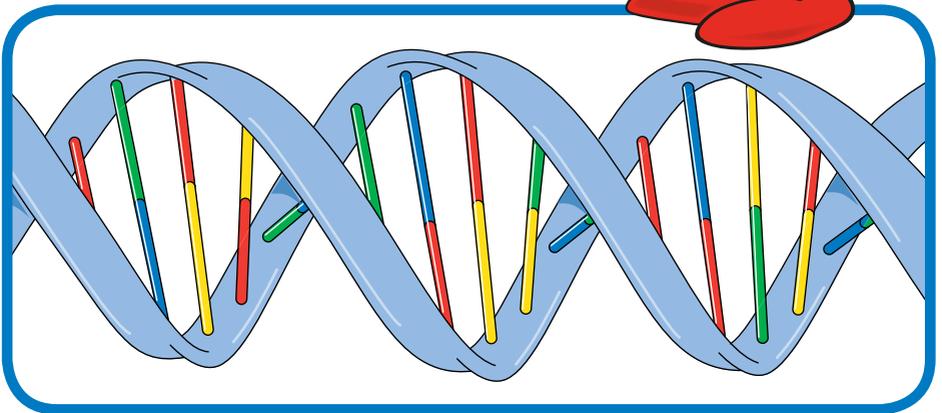
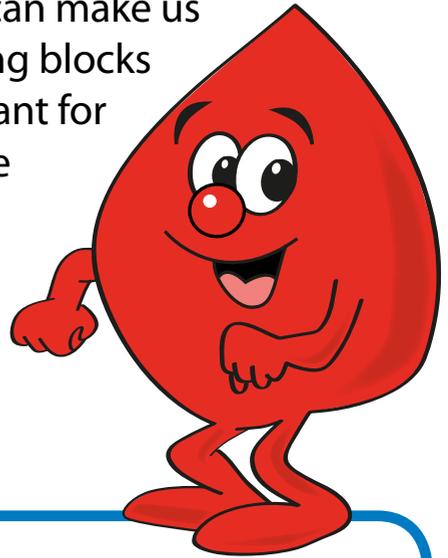
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Patient Information Leaflet

27/04/2012 Version 1

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

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 how our genes can make us unwell. Genes are the building blocks of your body and are important for keeping us healthy. The more we understand about these genes the more chance we have of stopping people becoming unwell.



Why me?

We are asking many boys and girls who 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 your blood or saliva. If you haven't had blood taken before then we can explain to 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 as much.

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. 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.

How often will I be contacted?

We wouldn't invite you to help us more than 4 times each year.

Where will the study take place?

A doctor or a nurse might collect a sample at your next hospital appointment or we might be able to visit you at your house. 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 convenient 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 and our doctors and nurses will know you're taking part.

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

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

It's OK if you decide to help us 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 appointments.

If I decide 'yes' - what next?

If you decide '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.