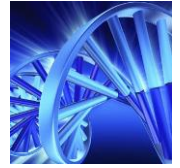




**PATIENT INFORMATION LEAFLET
FOR YOUNG PEOPLE 11-15YRS
NIHR BIORESOURCE - RARE DISEASES**



Version 1 27/04/12

Sometimes adults and children become unwell. Scientists, doctors and nurses work with young people and their close family to understand why this happens. We want to learn more about our genes and how our bodies work. Genes are the building blocks that determine things such as the colour of our hair, eyes and even the shape of our bodies. They also play an important role in maintaining our health. The more we understand about these genes the more chance we have of preventing and treating young people when they become unwell.

We would like to invite you to take part in our research. Before you decide if you would like to help please read this information sheet and talk to your mum / dad / the person who looks after you. You can also talk to your doctor or nurse if you want to. The leaflet explains why we are asking you to help and what it will involve for you. Thank you for reading this.

Why are we doing this research?

We would like to find the DNA code that causes your illness and to develop cheaper/quicker tests to allow the doctors to let other children know what is making them ill. In order to do this we are setting up a BioResource and we are inviting you to join.

Why have I been asked to take part?

We are recruiting young people with health problems from Hospitals or GP surgeries all over the UK. We need young people like you to help us get a better understanding of how genes affect our health and cause disease.

Do I have to take part?

No, taking part is up to you. It's OK if you don't want to take part and won't change any medical care you receive.

What will I be asked to do if I take part?

- Your doctor or nurse or member of the study team will ask you and your parents to sign a form giving your assent and your parents consent.
- You will be given a copy of this information leaflet and your signed form to keep.
- We will collect information about your medical and family history.
- We will ask you to donate a small blood sample (3-4 teaspoons) or saliva sample. If you haven't had blood taken or given a saliva sample before then we can explain to you how we do this. We can even put some cream or spray on your arm to make sure taking the blood doesn't hurt as much.

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 or ask your GP surgery to take a sample. You can chat to your mum / dad / the person who looks after you and decide. You can give saliva in the comfort of your own home. Your mum, dad or the person who looks after you can stay with you whilst we collect the sample if you would like.

When might I be asked to help?

A doctor or nurse will talk to you and your mum / dad / the person who looks after you and explain when a sample might be needed. 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 helping?

In addition to your own doctors, other doctors and nurses in the BioResource team will look at the information we collect when you're in hospital. No one else apart from your family and our doctors and nurses will know you're taking part. Your blood will be given a special number. The scientists who will look at your blood will not know who you are.



What will happen to any samples I give?

We will bring your blood sample into the laboratory and run a large number of different tests. Samples obtained from your blood will be stored for use in further research.

What are the possible benefits of taking part?

This study may not help you, but we hope that the information we obtain will help provide better treatment for other children and adults in the future.

What will happen next?

In the future we may contact you to invite you to take part in other studies. If you are invited to help with a study we will provide you and your family with full information about the study and be clear about what is involved. You will be free to decide whether or not you want to help. You don't have to take part if you don't want to.

How often will I be contacted?

We keep a close eye the number of times you are approached and invited to studies. The maximum number of invitations to studies will be 4 each year.

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 just tell one of the nurses, doctors or ask your mum, dad or guardian to let us know. You can still keep coming to the hospital or the GP surgery to see the doctors and nurses if you need their care.

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