



**PATIENT INFORMATION LEAFLET  
FOR YOUNG PEOPLE 11-15YRS  
Generation of induced Pluripotent Stem (iPS) Cells  
and Rare Diseases  
Version 1 07/06/2014**



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 use cells made from your donation to make many different cells in the laboratory. We would like to study these cells, and your genes, so that we can understand how to prevent and treat people when they become unwell.

**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 people to take part, to help us get a better understanding of how to prevent people becoming unwell.

**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/guardian to sign a form giving your assent and your parents/guardian 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 sample of skin\*and a blood (3-4 teaspoons) sample; it may also involve giving a urine or saliva sample. The doctor or nurse will fully explain how skin biopsies and blood samples are taken. We will inject the place on your arm where we will take the skin sample with an anaesthetic to numb the area, the majority of people don't feel any pain, and we will put a steri-strip (like a plaster) on top of the site to close it, no stitches will be needed. For the blood sample we can put some cream or spray on your arm to make sure taking the blood doesn't hurt as much.

***\*if there are medical reasons not to take a skin sample, then a blood sample may be ok instead, this will be discussed with you and your parents/guardian.***

### **Where will the study take place?**

A doctor or a nurse might collect a sample at your next hospital appointment, or you may have to travel to a different hospital. You can chat to your mum / dad / the person who looks after you and decide. 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 the samples 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, and members of the BioResource team will know you're taking part. Your samples will be given a special number when they arrive at the laboratory. The scientists who will look at your samples will not know who you are.

### **What will happen to any samples I give?**

We will bring your skin sample to a laboratory where it will undergo many processes aiming to make cells that can become any type of tissue, e.g. muscle, blood, liver, depending on the conditions under which they are grown.

The blood sample may be used to generate cells that can become any type of tissue, but it will also be used to run a large number of different tests. Samples obtained from your skin and blood will be stored for use in further research- they will not be stored with your personal details (name, date of birth, hospital number), but under a number ID.

### **What are the possible benefits of taking part?**

There will be no direct benefit to 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.

### **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.**