

What the study is about

(do ask for the adult study information sheet if you want more information)

We are doing a project to understand more about Russell Silver syndrome (RSS), which causes people to be shorter in height. We want to see how you are growing and developing, and find out more about you. This will involve some health checks.

Visiting our clinic

We will ask you not to have a meal for 6 hours (this might be overnight as normal when you are sleeping) before coming to see us so that we can measure your body's nutrients and test the genetics of RSS. The appointment is with a doctor who looks after children and young people.

Cheek swab & blood samples

We will get this over first. We rub the inside of your cheek with a swab, which is like a cotton bud. It does not hurt. Then we will ask you to let us take a small amount of your blood. We will put some cream on your arm first or use a spray. The cream and spray numb the skin so that you should not feel us take the blood with a needle. Once this is over you can have a snack.

The blood sample will be used to check your genetic make-up as well as other blood tests for sugar levels, fats and tests of how your kidneys and liver are working. We will do these to help us understand the results in RSS. We will let you and your parents know if we find problems. If there is anything your GP should do, we will ask your permission to contact him/her.

Talking

At our clinic we will talk and find out more about when you were born and if you have had any medical problems. The doctor will ask you lots of questions, for example about puberty and whether you take medicines.

Measurements

We will take measurements including your height, weight and skin thickness. We will also measure how hard you can squeeze with your hands and ask you to blow into a machine. To learn more about muscle and fat in your body we will pass a tiny pulse through one hand and one foot. All you will feel are the stickers. In some clinics, we can measure your body density. This is like having a picture taken and does not hurt. The first machine, called a 'DEXA' scan means you lie very still for a few minutes. The second machine is a type of scan where you put your arm or leg through a metal doughnut shaped machine and rest on the other side while the pictures are taken.

Checking over your body

The doctor will ask if we can examine you in the clinic and this will involve you taking off clothes to your underwear and letting the doctor listen to your heart and lungs and feel your abdomen. The doctor will be looking at whether puberty is complete as it tends to occur earlier in RSS. If you would prefer not to be examined for puberty, there will be a sheet you can use to tell us which stage you think you are at.

Your general health

We will ask you to fill in a short questionnaire telling us about your family and how you feel.

Photos

We would like to take some photographs of you (fully clothed). These will help us show how people with RSS look at different ages. The photos may be included when we write reports if you agree. Reports are also available online so these photos would be on the internet but your name would not be added.

Do I have to take part?

No. It's up to you. If you agree to take part and then change your mind, you can stop at any time. It won't change how your doctors look after you.

Any questions?

If you have any questions, please ask your mum, dad or guardian. They can phone us if they need more information.



Study for Adults and Adolescents with Russell Silver Syndrome in the UK (STAARS UK)

Information Leaflet 13-15 years old

CONTACT DETAILS

Wessex Clinical Genetics Service
Princess Anne Hospital
Southampton
SO16 5YA

Tel number: 02381 206551

Ethics no: 13/SC/0630

Version 2

Date:03/01/14