

# The ST RRY Study 2

A pilot study of Salivary cortisol and cortisone concentrations in women and girls with Turner Syndrome And unaffected female Relatives: Associations with cardiovascular and psychological health

## INFORMATION LEAFLET FOR CHILDREN AGED 8-12 YEARS

Your mum or dad or carer have talked to a doctor about a research study.

### Why is the research study being done?

We want to learn more about the health of girls who have Turner Syndrome. We think that girls who have Turner Syndrome might make more of a hormone (a chemical messenger in the blood) called cortisol. Cortisol is a really important hormone, it helps us to wake up in the morning, and if we are ill or injured, it helps us to recover. If people have cortisol levels that are a bit high, this might also make them more likely to have health problems in the future. We think that girls with Turner Syndrome might have higher cortisol levels than girls without Turner Syndrome and we would like to find out if this is true. This will help us to understand more about the best ways to help girls with Turner Syndrome to stay fit and healthy throughout their lives.

This study will help us to learn what girls with Turner Syndrome and their families or carers think about a research study that we would like to do in the future. In this future research study, we want to learn more about cortisol levels and the health of girls with Turner Syndrome. It is important that we do this, so that we can plan the best way to do our research. It will also give us some clues about whether we will find helpful information by doing a bigger study.

If you join the study and we find that your blood pressure was different to other young people, it wouldn't cause you any problems now, but we might ask your doctor to think about giving you some treatment to make sure it doesn't cause you a problem when you are an adult.

### **What will happen to me?**

While you are at the Turner Syndrome Support Society Annual Conference, we would like to invite you to take part in our research study. If you say yes, here's what will happen:

#### **Talking with you**

We will ask you a few questions about you about your health and any medicines you take. Don't worry - your mum, dad or carer can help with the answers. If they're not sure about something, and if you're happy with it, we can ask your doctor.

#### **Standing on special scales**

You will be asked to stand on some special weighing scales. These aren't just normal ones – they tell us cool things about your muscles and body fat.

#### **Blood pressure checks**

You might remember having your blood pressure checked by your doctor or nurse in clinic. We would like to check it too. A soft cuff is wrapped around your upper arm and gives it a tight squeeze. We'll do this three times, and we will show you how it works first so you know what to expect.

#### **Spit Samples**

We will ask you to give some small spit (saliva) samples three times on one day, either at home or while you are still at the conference. We will

show you exactly how to do this. If you collect these at home, we will ask your mum, dad or carer to post this back to Alder Hey. If you collect these at the conference, we can collect them from you there.

### **Who is doing this research?**

It is being run by doctors and scientists at Alder Hey Children's Hospital, Liverpool Women's Hospital, the University of Liverpool and Liverpool Centre for Cardiovascular Science.

### **Has anyone checked that this study is ok to do?**

Before any research can happen, it must be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. This research project has been checked.

### **Who do I ask about this?**

Your mum or dad or carer will be given lots of information. If they are not sure, the doctor who gave you this information leaflet can tell you more.