

Evaluation of Sleep in SYNGAP1-related Intellectual Disability Research Study Information Sheet

INTRODUCTION:

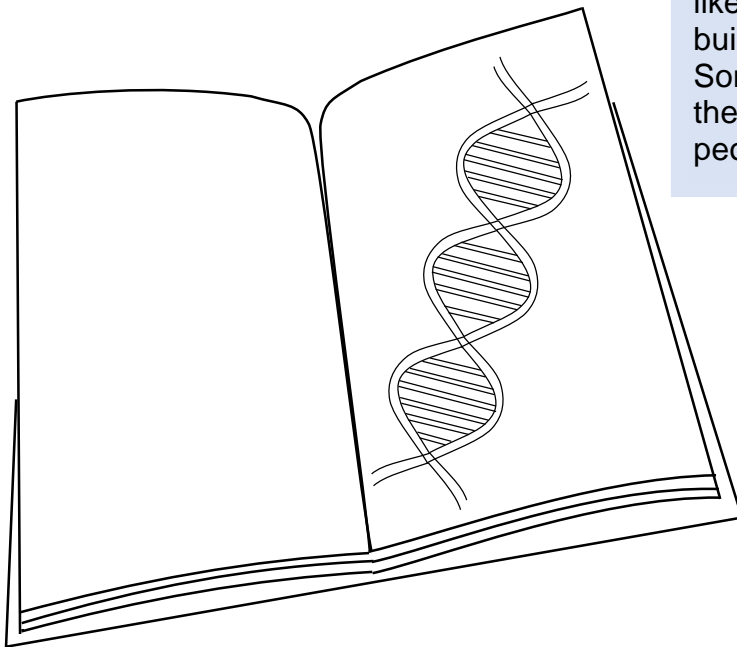
Parents and/or carers are asked to go through this information sheet with their child. Please ask study staff if you or your child has any questions.

We are asking if you would like to take part in a research study. In a research study people try to learn more about something or answer questions about it.

Before you decide if you would like to join in, it is really important that you read this sheet with your parents or carers to know what this study is about. You can ask us questions about the study and talk to your parents or carers about it. Then you can choose if you want to join in or not. Thank you for reading this.

What is research? What are we trying to find out?

- Research is a way we try to find out the answers to questions
- We are trying to find out how changes in a gene called SYNGAP1 affect sleep.



Your genes are part of your DNA like a codebook inside you for building your brain and your body. Sometimes very small changes in the gene code change the way people sleep.

Children with changes in SYNGAP1 can find it hard to learn and remember things, they can often be poorly and most of them have problems with their sleep.

We want to know why children with changes in SYNGAP1 have problems sleeping.

Why am I being asked to join in?

We are asking you because you have a change in SYNGAP1 or you know someone else who does.

Do I have to join in?

No. You can choose if you want to join in and you can always change your mind.

What will happen if I join in?

- We will ask someone who knows you well to answer questions about you and your sleep.
- We will also ask them to keep a diary of your sleep. You can help them.
- We will come to your house to study your sleep and how sleepy you are during the day. We will probably wear masks when we come. We will take a video of you sleeping and also ask you to wear equipment like this:



Will the study be helpful for me?

If you join in we will be able to tell you more about your sleep. We will also tell you if there are problems with your sleep that you should tell your doctor about in case they can help. You will also be helping us learn more about sleep in children with changes in SYNGAP1.

Are there any reasons not to join in?

It won't hurt to join in. Some people find it a bit strange or frightening to meet new people and do new things, but you can stop if you want to. We will send you pictures of us before we visit.

What do you do with my information?

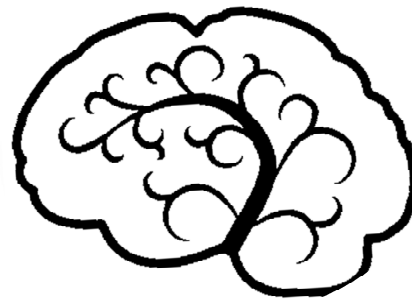
We keep it on paper and on computers at the University of Edinburgh where we work. We will follow laws to keep your information as private as we can.

What if something goes wrong?

We don't think the study will go wrong, but if it upsets you or makes you feel poorly you or your parents or carer can talk to Dr Lindsay Mizen who is running the study.

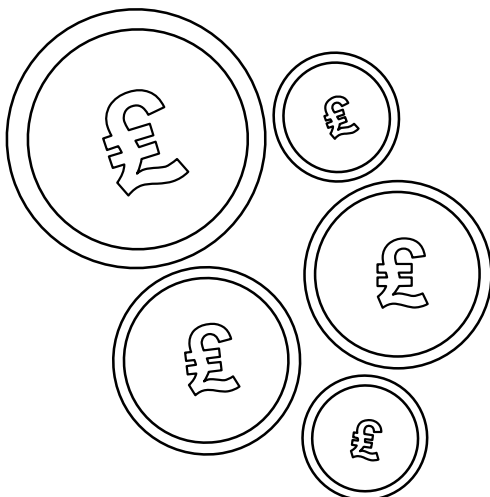
What will happen if I don't want to join in anymore?

You can stop if you want to and you don't need to tell us why. If you do stop then we will keep some of the information we already have about you, but we won't keep your name, address or any other things someone else might recognise.



What will happen at the end of the study?

- We will tell you what we have learnt.
- We will also write to tell science magazines and the people who paid for the study what we learnt.
- We will give talks to people about the study.
- We will never tell people about things like your name and address unless we ask you first.
- We will keep all the study information for 20 years in case we have new questions about it.



Who is running and paying for this research study?

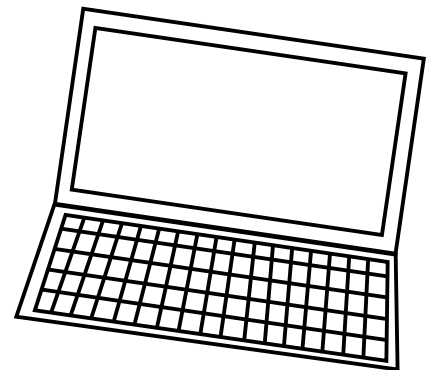
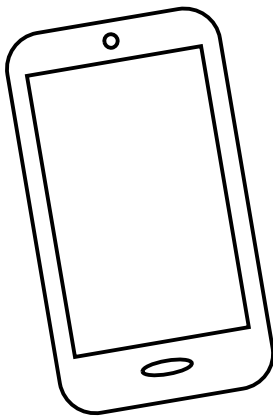
This study is being run by people who work at the University of Edinburgh.

The money to run the study comes from charities called the Simons Foundation and The Patrick Wild Centre.

Has anyone else checked it is ok to do the study?

The study has been checked by the people paying for it. A separate group of people called an 'ethics committee' have also checked it to make sure it is safe and that it will help us understand more about sleep in SYNGAP1.

**If you have any questions
you can talk to**



Dr Lindsay Mizen
She is running the study

Telephone:
0131 537 6263

Email:
lmizen@ed.ac.uk

Or Professor Stephen Lawrie - He is not doing the study, but could tell you about it and the people running it. Email: s.lawrie@ed.ac.uk Telephone: 0131 537 6771

If you aren't happy about the study tell your parents or carers.

Thank you for reading this sheet!