



University
of Exeter



Royal Devon
University Healthcare
NHS Foundation Trust

ENDURE

Understanding beta cell disorders through the
study of rare genotypes

A research study helping scientists to improve future
treatments for unwell people.



THE LEONA M. AND HARRY B.
HELMSLEY
CHARITABLE TRUST

DIABETES UK
KNOW DIABETES. FIGHT DIABETES.

JDRF IMPROVING
LIVES.
CURING
TYPE 1
DIABETES.

Chief Investigator: Professor Andrew Hattersley

ENDURE Study Information Leaflet

What is a research study?

A research study is work scientists do to learn more about something, or to find out something new. It can help doctors and nurses to find out the best way to treat people who may need help.

Why are we doing this research study?

This study is important because it could help us understand more about people who have diabetes or similar conditions.

This new understanding may help us know how to look after them better.

Why have I been invited?

You have been invited into this study because you have a type of diabetes or similar condition that we are studying.

Or you are healthy and are close in age to someone with a condition, so that we can learn about the differences between you.

What does taking part involve?

- You will come to see us at a hospital or clinic.
- We will explain about the study and what being part of it involves. Then we will ask you and the person who looks after you if you agree to taking part.
- If you agree, we will collect a blood sample from your arm.
- If you would like, we will put some special cream or spray on your arm so that you don't feel it when we take the blood sample.
- We will ask some questions about your health and measure your height and weight.
- We may also ask you to go into a special machine that takes pictures of the inside of your body.

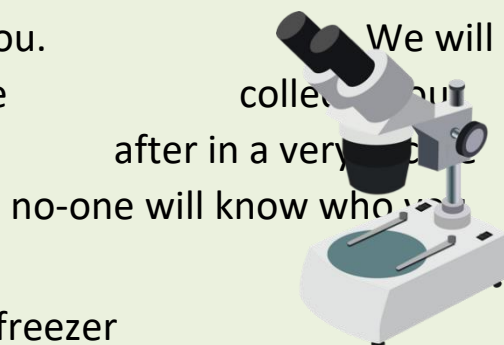


This Photo by Unknown Author is licensed under CC BY-SA

What will happen to my samples and information?

A study number will be created that is only for you. We will use this on your samples and the information we collect about you and will make sure that they are looked after in a very safe way to protect them and so that no-one will know who they are.

Your blood samples will be stored in a very cold freezer and some scientists will study them. We will ask you if it's OK for us to keep any sample leftover for use in other studies in the future. If we find out new things by doing this study, we will write about it in articles for other researchers to learn about them.



Do I have to take part in this study?

No. If you don't want to take part, that's OK and we will not mind.

If you agree to taking part, we will ask you to write your name on a form to say this. We will also ask the person who looks after you if they agree too.

You can change your mind and stop taking part at any time and won't have to tell us why.

Has anyone checked that this research study is OK to do?

Yes, all research studies are checked by a group of people called a Research Ethics Committee.

Will other people be told information about me?

We will tell your doctor if we find anything that would affect your care. We will look after your information carefully and will not tell anyone else.

Who can tell me more about this study?

If you or the person who looks after you have questions at any time, you can speak to a member of our study team.



Thank you for reading this leaflet, which is yours to keep.

If you are happy to take part in this study and the person who looks after you also agrees, you will be asked to write your name on a form that will have the statements shown below.

ASSENT STATEMENTS

- I have been given the study leaflet to keep and I have read it or had it read to me.
- I have asked all the questions I want to and my questions have been answered in a way I understand.
- I agree to take part in this study.
- I understand that I can change my mind at any time and can stop being part of the study.

You can say 'No' to the next statements and still take part in the study.

- I agree for my information and any leftover samples to be kept for use in other studies.
- I am happy to be contacted about research in the future.

We will give you and the person looking after you a copy of the assent form to keep.

**Thank you for reading about this study
and for thinking about helping us.**

