

EXE-T1D

Understanding beta-cell destruction through the study
of Extremely Early-onset Type 1 diabetes

**A research project helping scientists to
understand why some people develop Type 1
diabetes when they are very young.**



What is a research project?

A research project is something we 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 children who may need their help.

Why are we doing this research project?

We want to find out why some children get illnesses like diabetes very young. This is important because it could help us understand more about diabetes and to look after young people with diabetes better.

Why have I been chosen?

You have been invited into this study because you were diagnosed with diabetes or autoimmunity very young.

What does participation involve?

- We will arrange to see you at the hospital, clinic or at home, or may ask for you for some blood from a fingerprick when you test your blood sugar at home.
- We may give you a pot to collect some urine (wee) in.
- 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 a blood sample.
- Then we will ask some questions about your health and measure your height and weight.

What will happen to my blood and urine sample?

Your blood and urine (wee) samples will be given a special study number and stored in a freezer and some scientists will study them.

We will ask you if it is OK to keep anything that is left over for other projects in the future.

Do I have to take part in this project?

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

If you do want to take part, we will ask you to write your name on a form, like the one on the next page, 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 else checked that this research project is OK to do?

Yes, all research projects are checked by a group of people called an 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 project?

If you or the person who looks after you have any questions, you can phone and speak to a member of our study team. Our telephone number is:

01392 408181

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

If you are happy to take part in this study, you and the person who looks after you will be asked to **sign a consent form which will include the following statements:**

CONSENT STATEMENTS

- I have read this leaflet 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 am happy to take part in this project.
- I understand that I can change my mind at any time and stop being part of the project.

The next question is not essential and you can say no but still part.

- I agree for information about me and any leftover samples to be kept for use in other projects.
- 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 form to keep.

Thank you for reading about this project and for thinking about helping us.