

Parent/Guardian of [Child's name]
Address

[Site address
Tel:
Email:]

Date:

Dear Parent/Guardian of [Child's name]

Re: EXE-T1D Study: Understanding beta-cell destruction through the study of
EXtremely Early-onset Type 1 diabetes (A Musketeers' Memorandum Study)

Thank you for agreeing to help with our EXE-T1D research study aiming to improve understanding of extremely early-onset Type 1 diabetes.

As arranged, [Child's name]'s appointment is at:

Time:

Date:

Location:

Please find enclosed information sheets to give you more details about the study. As explained, during the visit, we will need to obtain certain samples and information from you and [Child's name] that will involve the following:

- Completion of a consent form to participate in the study, following discussion about the study
- Height and weight measurements
- Questions about the diagnosis of your child's diabetes, details of their birth and family history of diabetes.
- Blood samples
- Urine sample (collection pot and instructions enclosed)

I have also enclosed a tube and instructions for collecting a urine sample - see overleaf. This is an optional sample which would be helpful for our research if collected [but, due to your child's age, we understand this may not be possible].

If you have any queries in the meantime, please do not hesitate to contact our study team [at the NIHR Exeter Clinical Research Facility on 01392 408181].

With many thanks for your help.

Yours sincerely

[Staff name]
EXE-T1D Study Team

Enc. EXE-T1D Information Sheet - Study 1 Parent / Study 2 Parent (*delete as appropriate)
EXE-T1D Information Sheet - Child 5-7 yrs / Child 8-12 yrs / Young Person (*delete as appropriate)
[Urine collection pot]

EXE-T1D Study**Instructions for collecting a urine sample at home (for a UCPCR test)**

Please collect this urine sample on the day before your child's appointment.

1. Please encourage your child to pass urine just before their biggest meal of the day and discard.
2. They should eat their meal as usual with a glass or more of water
3. They should not eat or drink anything else for the next 2 hours (unless they go hypo – in which case, please do the test on another day).
4. On the label of the red-topped sample tube provided, please write your child's name, and the date and time that the sample is collected.

NOTE: The red-topped sample tube contains small white crystals - this is a preservative, so please do not discard it.

5. **2 hours after this meal, please encourage your child to go to the toilet and pass some urine into the red-topped tube provided.** It may be easier to collect the urine in a *clean* larger container first from which urine can be added to the tube. *Screw the lid on securely.* If your child can't last 2 hours after their meal, please collect the sample when they need to urinate.
6. Put the red-topped tube into the plastic bag provided, which contains some absorbent paper material, and make sure you close the bag's 'zip lock' securely.
7. **I will collect the sample at the appointment.**

Thank you for your help.

If you have any questions, please contact a member of the study team on:

Tel: [01392 408181]

The study team is available from [8am – 4.30pm Monday – Friday].

[Site address]