

**Genetic Beta Cell Research Bank**  
**Information Sheet for Parents & Child (Version 1 01.09.2017)**

**What is the Genetic Beta Cell Research Bank?**

It is a database and bank of biological samples to study the causes, diagnosis and treatment of diabetes and other beta cell disorders. [The beta cells are the parts of our body that usually make insulin.] It is managed by a world leading team of diabetes geneticists and doctors and kept within a secure NHS setting. The bank is governed by a committee of experts and patient representatives who must approve all uses of samples and data within the bank.

**Why have I been invited to read this information sheet?**

You have been invited because your child is eligible to donate samples to the Genetic Beta Cell Bank. Please read the information provided and discuss it with your child. We have provided simplified information overleaf suitable for younger children, which may be useful when making a decision with them about whether they would be happy to participate.

**Why are we looking for donors to the Genetic Beta Cell Research Bank?**

In order to understand more about the way that beta cells control insulin and the genetic causes of diabetes, we need to build up a bank of genetic material (DNA and or RNA) and biological samples from people who have diabetes and related conditions, and from their friends and relatives who do not have these conditions.

**What does donation to the Genetic Beta Cell Research Bank involve?**

Your child will be asked to donate one or more of the following samples to the bank:

- \* A fresh blood sample (up to 6 teaspoons)
- \* Access to a blood sample that has already been taken for diagnostic purposes
- \* A saliva or mouth swab sample
- \* A urine sample

The number and type of sample requested will depend on the age of the volunteer and the needs of the research and will be chosen to minimise burden to the volunteer.

Consent will also be asked for NHS staff to be able access your child's medical notes so that samples can be linked to their medical history.

On this occasion we would like donation of the following:

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**What will happen to my child's samples and data?**

When samples and personal information are donated, they will be given a research code. This means that research staff working outside of the NHS will not be able to identify the sample and information as belonging to the donor. The samples and data will be stored in a secure facility and their use will be governed by a Steering Committee who will ensure that they are used only by experienced teams working on approved studies examining the mechanism, cause, diagnosis and treatment of diabetes and other beta cell disorders.

**What will happen if we discover something relevant to your child's clinical care?**

If, as a result of our research, we find out something that their doctor should know, we will inform them.

**What are the risks of participation?**

If blood samples are required, they will be taken by fully qualified personnel who are covered by NHS indemnity for negligent harm. Any potential discomfort or side-effects will be equivalent to that experienced giving a blood sample to your GP.

**What are the benefits of participation?**

Donors with diabetes are more likely to benefit personally from this research as improvements in understanding may help to improve treatment. All donations are made as a gift to research, with no expectation of financial personal gain.

**What if there is a problem?**

We will address any problems that might occur during your child's participation in the study. The research team will be happy to discuss with you any concerns and our contact details are given at the end of this information leaflet. However, if you have concerns or complaints arising from your child's experience of participating in this study which you do not wish to discuss with the research team directly, the Patient Advice and Liaison Service (PALS) will provide independent advice, help address your concerns and liaise with the appropriate members of the RD&E NHS Foundation Trust on your behalf. Contact details for the local PALS service are given below. We do not anticipate any adverse events related to their health following your child's participation in this project. However, if they experience any problems we would be happy to be contacted to discuss them.

**Does your child have to take part?**

No, participation is entirely voluntary. It is up to you to decide with your child whether they would want to provide samples. Samples can be withdrawn at any point.

**Ethical Review**

This study has been reviewed by the North Wales Research Ethics Committee who specialise in reviewing this kind of study. The members of the committee are satisfied that all ethical requirements have been met.

**Who can I contact to find out more about this study?**

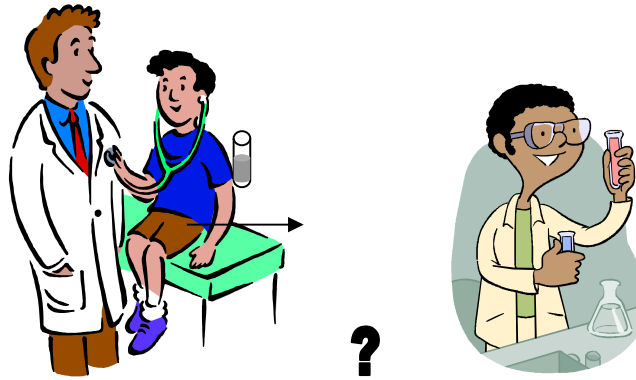
If you have any questions please contact:

Dr Bridget Knight  
NIHR Exeter Clinical Research Facility, Level 2 RILD,  
Barrack Road, Exeter, EX2 5DW  
Telephone: 01392 408172  
E-mail: [B.A.Knight@ex.ac.uk](mailto:B.A.Knight@ex.ac.uk)

***If you would like to discuss this project with someone other than the researchers please contact:***

PALS (Patient Advice and Liaison Service) by telephone, email or in writing at:  
PALS Office, Royal Devon and Exeter NHS Foundation Trust, Barrack Road  
Exeter, EX2 5DW  
Telephone: 01392 402093  
Email: [rde-tr.PALS@nhs.net](mailto:rde-tr.PALS@nhs.net)

## SIMPLIFIED INFORMATION



Would you be happy to give some samples to scientists at the Royal Devon & Exeter Hospital so that they can try and understand more about why people get sick and is it OK if they contact you about joining in their projects in the future?