

TEDS Research Centre
FREEPOST LON7567
LONDON
SE5 8YZ
FREEPHONE 0800 317029
email teds@iop.kcl.ac.uk



Dear PARENT FORENAME

Thank you for your continuing involvement in TEDS. We hope very much that you will be able to help us with the next stage of the project. This involves collecting DNA from TWINA FORENAME and TWINB FORENAME which will be analysed to help us learn more about the genetic factors that play a part in the development of human language, thought and behaviour.

As you may have seen in the current TEDS newsletter, DNA research is especially valuable for TEDS because there have been some huge advances recently in the ability to find genes that affect development. For example, you may have heard in the news about major findings from studies that analyse hundreds of thousands of bits of DNA across all the chromosomes (called genome-wide association) for very large samples like TEDS. The ability to conduct DNA studies is especially valuable for twins like yours who have participated in TEDS over the years, including the recent 12-year web-based testing. For this reason, the purpose of this letter is to ask if you would be willing for the twins to send us a cheek swab so that we can use their data in our DNA studies.

Enclosed is a pack for collecting the DNA. It is very simple and quick to do. All we ask you to do is to rub the inside of your twins' cheeks with cotton buds and then place the cotton buds in the small storage tube. It doesn't hurt at all - but might tickle a little! The leaflet enclosed with this explains how to do it in a little more detail. You can send the two storage tubes back to us in the freepost envelope. Once it reaches the labs, the DNA is extracted from the nuclei of the cheek cells.

As always any information you give us will be treated as strictly confidential. The data from the DNA will be used anonymously and at the end of the study, any remaining DNA will be destroyed. If you would like any more information or if you would like to discuss this study further, please give us a call on our freephone number (0800 317 029) or email us at teds@iop.kcl.ac.uk and we will be happy to help.

If you do not wish to participate, could you please tick the box on the form enclosed and return it to us so that we can make sure we do not trouble you with reminders. **You will still be part of TEDS if you choose not to take part in this DNA study.**

Please make sure that you send back the consent form with the tubes – if we do not have your signed permission, we can't use the DNA you are kind enough to send us. Please also ensure that you use all 10 cotton buds for each twin.

Many thanks for your continuing support that makes our research possible

Yours sincerely,

A handwritten signature in black ink that reads "Tricia Busfield". The signature is written in a cursive style and is enclosed in a thin black rectangular border.

Tricia Busfield (TEDS Research Co-ordinator.)

Family ID:

DNA CONSENT FORM

If you and your twins would like to help with the TEDS DNA study it is important that you sign this form. As in all research, we can only involve you if you sign.

When you sign this form, you are agreeing to collect cheek cells from your twins with the cotton wool buds provided for use in the TEDS DNA study.

We would like to use the DNA to look at aspects of development such as learning language and other new skills. We cannot give you results from the DNA study (apart from the zygosity test offered below). The DNA will be used for research purposes only, not for clinical tests. The DNA will be destroyed at the end of the study.

Your family reference number:

Your name

Relationship to the child (e.g. mother, guardian etc)

Your address Address

Tel:

YES, I agree to myself and my twins helping with the TEDS DNA study. I understand that we can withdraw at any time, and that all information will be kept strictly confidential.

If your twins are the same sex, and you would like us to tell you if they are identical or not, put a tick in the box.

(Please be aware that it may take up to six months for you to receive these results)

Signature **Today's date**/...../..... (Day/Month/Year)

No, I don't want to take part in the DNA study.

Collecting Mouth Cells

Your pack contains:

2 tubes containing storage liquid – one for each twin.
20 cotton wool buds – 10 for each twin.

**AS WITH ALL SMALL OBJECTS AND UNDRINKABLE LIQUIDS,
PLEASE KEEP OUT OF REACH OF CHILDREN AND PETS**

Collecting mouth cells is very easy and is best done **FIRST THING IN THE MORNING** - before the children have eaten or drunk anything or brushed their teeth. This is the best time because it makes sure that we get lots of mouth cells and **NO BITS OF FOOD!** Please try to use all ten of the buds for each twin. You may find it easier to use all ten on one day, but it does not matter if you do it over two days.

PLEASE NOTE: It is important to keep the twins' mouth cells separate. We have labelled the tubes with each child's name. Please be careful not to muddle them up!

Each pack has a limited life span so please use and return to us as soon as possible.

How to Provide a DNA Sample

- 1). Take a cotton bud and rub it gently around the inside of the mouth (including cheeks, inner lips and gums) with a little pressure against the mouth. Try to do this for about 20 seconds with each bud.
- 2). Make sure that you get good coverage of the mouth. Each time you use the buds, try to use half of them to rub the left side of the mouth, and half the right.
- 3). Each time a bud has been used, please place it in the tube containing the storage liquid – cotton wool end downwards, into the liquid.
- 4). Make sure it is labeled with the right twin's name. Be sure to do the lids up tightly. Store the tubes at room temperature (NOT the fridge!) and away from direct sunlight.
- 5). When all 10 buds have been used **for each twin** and put in their tubes, please put both of the tubes and the **signed consent form** in the Freepost envelope provided and post back to us as soon as possible.

DON'T FORGET TO CHECK YOU ARE USING THE RIGHT TUBE
FOR EACH PERSON

THANK YOU FOR YOUR HELP.

Questions? Call our Freephone: 0800 317 029