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**Oxford Study of Children's**

**Communication Impairments**

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**Information about this research study into why some**

**children have language, reading and communication problems**

We would like to invite you to take part in a research study. Before you decide whether to take part, it is important for you to understand why this study is being done and what it will involve. Please take time to read the following information carefully and discuss it with other family members. Ask us if there is anything that is not clear or if you would like more information.

**What is the purpose of the study?**

We want to find out more about why some children have difficulties with learning to talk, understand language or read. People often assume this is caused by the child’s environment. However, our research, and that of others, shows that genetic differences between children can be important. Twin studies can help as they allow us to compare development in two children growing up together.

**Why have I received this information sheet?**

We have asked Head Teachers in England to send this leaflet to parents/guardians of twin children who are pupils at their school. We want to include both identical and non-identical twins. We are interested in twin pairs where one or both children are having difficulties with reading or language, but we are also seeing twin pairs who are not having any problems.

**Do I have to take part?**

It is up to you and your children to decide whether or not to take part. We recommend that parents/guardians and their twin children view a short video about the research before making a decision. We can send a DVD of the video on request, and it can also be viewed on:

<http://www.youtube.com/watch?v=QdDxfY2ZvE0>

If you do agree to take part, you will be asked to sign a consent form, but you can withdraw at any time without giving a reason. A decision to withdraw, or a decision not to take part, would not affect your children’s education in any way.

**Who can take part?**

Only twins aged between 6-11 can take part in this project. If you are interested in taking part but your twins are not yet 6, but will be by 2015, please still contact us.

This study is also focusing just on children who speak English at home as their main language. This is because our language assessments are in English and could give misleading results for other children.

**What will happen if I give permission for my children to take part?**

* One of our research team would telephone you to go through the information sheet with you and answer any questions you have.
* We would also ask you about your child’s medical history, hearing, and educational progress, to check if the children are suitable for the study. If so, and you are happy to go ahead, we would arrange to come to see the twins for an assessment lasting around 3 hours.
* The assessments can be done at school, if the head teacher is willing, but we are also happy to see children at home. In our experience, most children are happy to be seen alone, but a familiar adult can be present if they wish.
* We assess language by asking the child to repeat words or sentences, or point to a picture to match something that the adult says. We also give a short reading assessment. These tests are digitally recorded for later scoring.
* Some tests look at reasoning using patterns, and do not involve any language. Most of the assessments start with easy items and then get harder. Testing stops when the test gets too difficult for the child.
* We would also do a test to measure blood flow to the two halves of the brain while the child tells a story. This is to see which half of the brain works hardest when the child completes the language task. This method is shown here on the right and on the information video. It requires the child to wear an unobtrusive headset while they watch videos on the computer. Finally, we will take saliva samples by asking the children to spit into a special pot. This will allow us to extract DNA from the saliva.
* DNA samples will be processed by Professor Simon Fisher in Nijmegen, Netherlands.
* It is likely that in future other genes will be discovered that are relevant to our study. Therefore we are asking parents to give general permission for us to use their children’s DNA to look at the effects of genes relevant to children’s brain development.
* We would also ask you to fill in two questionnaires about communication skills. Together these take about 30 minutes to complete for each twin. There is also an online questionnaire about general behaviour and development. This takes between 10 and 30 minutes to complete for each child.

**What are the possible disadvantages and benefits of taking part?**

There are no risks in taking part in this study. In general, the research does not directly help the children who take part. However, you could be involved in an important scientific advance and our findings could help children with language or literacy problems in the future. To say thank you for giving up your time, we give participating families a small gift.

**Will I get feedback about my children’s results?**

We do not usually give detailed feedback. However, if we identify specific language or related problems that haven’t already been picked up, we will discuss this with you and write a report describing our findings if you wish.

We can also tell you whether your twins are genetically identical on our DNA test, though we will only be able to do this at the end of the study. We are unlikely to find any specific genes that can explain a child’s difficulties. This is because in most cases of language and communication, problems aren’t caused by a genetic disease. Instead they are influenced by many genes acting together. These genes vary from person to person, and each has only a small effect.

**Will the results be kept confidential?**

* Questionnaires and test results from our study are identified only by a code number, and kept in a locked filing cabinet.
* Digital recordings are anonymised and stored on a personal computer. Personal information is kept strictly confidential. DNA is identified only by a code number.
* Test results and DNA will be made available to other researchers only after all identifying information has been removed.
* If you withdraw from the study, your child’s data and DNA will be destroyed.
* Responsible members of the University of Oxford may be given access to data for monitoring and/or audit of the study to ensure we are complying with regulations.

**What happens to the results of the research study?**

The results will be analysed and reported in scientific journals. Summaries of the findings will be featured in our newsletter.

**What will happen to the DNA samples?**

These will be anonymised and stored by Professor Simon Fisher, Director of the Language and Genetics Group at the Max Planck Institute for Psycholinguistics in Nijmegen in the Netherlands.

**What happens when the research study stops?**

We hope the results from our study will be used by other researchers, but before making anything public, all identifying information is removed, so it is not possible to trace the results back to a specific child. When the research study stops, we will transfer these anonymised results to a public database, so they can be used for future studies. DNA will be securely stored at the Department of Language and Genetics at the Max Planck Institute for Psycholinguistics in Nijmegen, Netherlands.

**What happens if there is a problem?**

If you have any concern about any aspect of the study, you should speak to the researchers who will do their best to answer your questions. The University is the Research Sponsor for this study. It has arrangements in place in case any harm arises from taking part in the study. If you wish to complain about how you have been approached or treated in the course of this study, you should contact Professor Dorothy Bishop (address above). You may also contact the University of Oxford Clinical Trials and Research Governance Office on 01865 857939, or by email to heather.house@admin.ox.ac.uk.

**Funding and approval of this research**

The study is part of a research programme by Professor Dorothy Bishop of the University of Oxford, and is funded by the Wellcome Trust. This study has been reviewed and given favourable opinion by the Berkshire Research Ethics Committee.

**What to do next**

If you decide not to take part, you need not do anything. If you would like to take part, please either fill in the enclosed form and return it by post to the Freepost address provided, or telephone us, or complete our online form, which can be found at: http://oscci.psy.ox.ac.uk/research-programme/twins-study

**How to contact us**

If you would like to discuss any aspect of the research, or if you have questions afterwards, the first point of contact is:

Holly Thornton, Department of Experimental Psychology, South Parks Road, Oxford, OX1 3UD.

Tel: 01865 271386; Email: oscci@psy.ox.ac.uk.

***Thank you for reading this***