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INFORMATION SHEET

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TEDS Myopia Study

We would like to invite you to participate in this original research project. This study has been approved by the King's College London Psychiatry, Nursing and Midwifery Research Ethics Committee. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. If you have any questions then please feel free to contact us by email or on our Freephone number.

Research Aims

Myopia, or short-sightedness, occurs when the image of a distant object is focused in front of the retina. This results in the observer seeing a blurred image and requires correction in the form of glasses or contact lenses. Myopia is the commonest eye condition worldwide, a leading cause of poor sight and the number of people with the condition is increasing.

We know there is a link between education, close work, intelligence, lack of outdoor activity and myopia. The aim of this study is look more closely at these influences using the unique TEDS twin study, which is probably the only study in the world able to answer these important questions.

Who Have We Asked to Participate?

We are inviting all TEDS twins to be involved in this study, whether you wear glasses or not. There are no restrictions on taking part in this study. While we would encourage both twins to return the questionnaire, as this broadens the range of analyses we can do on the data, we do not require that both twins participate. Responses from one twin alone will still be useful for our research.

What does taking part involve?

If you agree to take part in this study we will ask two short questions regarding your eyesight and if you wear glasses or contact lenses. We will then ask permission to contact the optician at which your most recent eye test was performed, in order for us to collect accurate data on eye health. It should be noted that those under 16, or aged 16 to 18 and in free full time education qualify for a free NHS funded eye test. Parents can complete the questionnaire but we would be grateful if the twin signs the consent form, particularly for those twins now over 18 years of age.

Included in this pack are a questionnaire and a consent form. **This must be completed and signed by the parent for those under the age of 16, or for those now over the age of 16 by the twin with preferably the parent signature as well.** On completion, these can be returned to us in the freepost envelope enclosed. If there are any questions that you would prefer not to answer then please feel free to leave them blank. It is expected that completion of the questionnaire will take around five minutes.

Are There Any Risks Involved in Participating?

The research entails no risk beyond those of ordinary life. The questions are quite benign and all participants are instructed to leave items blank if they are uncomfortable about answering them.

Are There Any Benefits Involved in Participating?

At the conclusion of the project we will publish our most significant findings on the TEDS website so that you can access them (www.teds.ac.uk). We will also use the website to alert you to any research publications we have generated from the project.

How Will We Maintain Your Privacy and Confidentiality?

All the data that your family provides are strictly confidential; your twins are identified only by a number in the study datasets. Identifiable data will be only accessed by authorised persons in the TEDS team and stored in a separate secure location. The data your family provides will be kept for a minimum of 10 years after completion of the TEDS study, as recommended by the Medical Research Council (MRC). The data may be shared with other researchers, but only after removing identifying information about the participants. We will not pass your family's information on to any other organisations. The data may be retained for use in future studies subject to further ethical approval.

Who is Organising and Funding the Research?

The TEDS Myopia Study is being organised by Dr Katie Williams, working with Professor Robert Plomin of the TEDS study and Professor Chris Hammond of the Department of Ophthalmology at King's College London. The study is being funded by King's College London.

Do you have to take part?

It is up to you to decide whether or not to take part. If you do take part, you are free to withdraw yourself during the study period (September 2012 to August 2013) without giving a reason. Your decision not to take part in this study will not affect your future involvement with TEDS.

Queries?

If you have any questions or if the study has harmed you in any way do not hesitate to call us (Dr Katie Williams - the study lead, Professor Robert Plomin and the TEDS Team) on our freephone line 0800 317 029, or email us at teds-project@kcl.ac.uk.

Thank you from all at TEDS!