Variability of preschool stuttering during play

PARENTAL INFORMATION STATEMENT

(1) What is this study about?

Your child is invited to take part in a research study investigating children’s stuttering under varying conditions, such as gentle background noise, while they are playing.

Your child has been invited to participate in this study because he/she is a preschool aged child who stutters. This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to let your child take part in the research. Please read this sheet carefully and ask questions about anything that you don’t understand or want to know more about.

Participation in this research study is voluntary, so it is up to you whether you wish to let your child take part or not.

By giving your consent you are telling us that you:

✓ Understand what you have read
✓ Agree for your child to take part in the research study as outlined below
✓ Agree to the use of your child’s personal information as described.

You will be given a copy of this Parental Information Statement to keep.

(2) Who is running the study?

The study is being carried out by the following researchers:

• Professor Mark Onslow, Chief Investigator
• Dr Susan O’Brian, Co-investigator
• Dr Robyn Lowe, Co-investigator
• Rachel McMillan, speech pathology honours student
• Artemi Kokolakis, administrative support
Rachel McMillan is conducting this study as the basis for the Honours component of the degree of Bachelor of Applied Science (Speech Pathology) at The University of Sydney. This will take place under the supervision of Professor Mark Onslow, director of the Australian Stuttering Research Centre.

(3) **What will the study involve?**

Participation in this study involves you and your child attending one session for approximately 1.5 hours at the Australian Stuttering Research Centre, the University of Sydney, Lidcombe. You, your child and the clinician will engage in two 15-minute play sessions together. There will be a 45 minute rest period between the two play sessions. Your child’s speech will be audio and video recorded during the play sessions.

(4) **How much time will the study take?**

The study will involve you and your child attending the Australian Research Centre, the University of Sydney on one occasion for about 1.5 hours. **At the conclusion of your involvement in the study, you will be offered a $50 Coles Myer gift voucher as compensation for your time.**

(5) **Who can take part in the study?**

Children who stutter

- Aged between 3.5 and 5 years
- Stuttering confirmed by a speech pathologist
- Stuttering to meet a minimum criterion that will be assessed prior to entry in the study
- No previous or current treatment for stuttering
- Stuttering onset at least 6 months prior to entry into the study
- Both child and parent proficient in English
- No other medical or behavioural problems
- No other speech or language disorders

(6) **Does my child have to be in the study? Can they withdraw from the study once they’ve started?**

Being in this study is completely voluntary and your child does not have to take part. Your decision whether to let him/her participate will not affect your/their relationship with the researchers, speech pathologists or anyone else at the University of Sydney, now or in the future.

If you decide to let your child take part in the study and then change your mind later (or he/she no longer wish to take part), he/she is free to withdraw from the study at any time.

If your child withdraws from the study, we will not collect any more information from him/her. Please let us know at the time of withdrawal what you would like us to do with the information we have collected about him/her up to that point. If you wish, his/her information will be removed from our study records and will not be included in publications.

(7) **Are there any risks or costs associated with being in the study?**

Aside from giving up your and your child’s time, we do not expect that there will be any risks or costs associated with taking part in this study for you or your child.
(8) **Are there any benefits associated with being in the study?**

We cannot guarantee or promise that your child will receive any direct benefits from being in the study.

(9) **What will happen to information that is collected during the study?**

By providing your consent, you are agreeing to us collecting personal information about your child for the purposes of this research study. Their personal information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

Your child’s information will be stored securely and their identity/information will be kept strictly confidential, except as required by law. Study findings may be published, but your child will not be individually identifiable in these publications.

The audio and video recordings of your child will be analysed by the researchers involved in this study.

The data and results will be compiled to form a student thesis as a requirement for the degree of honours. The group results may be published in a scientific journal and may be presented at domestic or international conferences. During and after the study, the data collected will be stored in secure locked locations within the Australian Stuttering Research Centre where only the researchers involved in the project will access it.

We will keep the information we collect for this study, and we may use it in future projects. We don’t know at this stage what these other projects will involve. We will seek ethical approval before using the information in these future projects. All data will be ultimately disposed of permanently and confidentially, by being shredded or erased.

(10) **Can I or my child tell other people about the study?**

Yes, you are welcome to tell other people about the study.

(11) **What if we would like further information about the study?**

When you have read this information, Professor Mark Onslow and Rachel McMillan will be available to discuss it with you further and answer any questions you may have. If you or your child would like to know more at any stage during the study, please feel free to contact Professor Mark Onslow, Chief Investigator by email mark.onslow@sydney.edu.au or phone 9351 9061

(12) **Will we be told the results of the study?**

You and your child have a right to receive feedback about the overall results of this study. If you would like to receive feedback on the group results, you can request discussion of these from the researchers. You can also tell us other ways that you wish to receive feedback on the results of this study by ticking the relevant box on the consent form. You will receive this feedback after the study is finished.

(13) **What if we have a complaint or any concerns about the study?**
Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney [INSERT protocol number once approval is obtained]. As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research* (2007). This statement has been developed to protect people who agree to take part in research studies.

If you (or your child) are concerned about the way this study is being conducted or wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

- **Telephone:** +61 2 8627 8176
- **Email:** ro.humanethics@sydney.edu.au
- **Fax:** +61 2 8627 8177 (Facsimile)

*This information sheet is for you to keep*