PARTICIPANT INFORMATION STATEMENT

HREC Project Number:	HR45/2013
Project Title:	*OCD, Autism, Adolescents and Online Treatment Program*
Chief Investigator:	*Dr Rebecca Anderson, Clinical Psychologist*
Student researcher:	*Lisa Wallace, Provisional Psychologist*
Version Number:	*Version 1.1*
Version Date:	*11/06/2017*

What is the Project About?

We are investigating if an online treatment program with face-to-face support can be helpful for adolescents with both autism spectrum disorder (ASD) and obsessive compulsive disorder (OCD). Online programs have been found to be helpful in reducing symptoms of OCD in children without ASD, however there has been little investigation into what is helpful for those with OCD and ASD. Additionally, we are investigating if participation in this program reduces stress in parents and improves family relationships.

Who is doing the Research?

The project is being conducted by Lisa Wallace, and the results of this research project will be used as part of the requirements to obtain a Master of Clinical Psychology. The research is supervised by Dr Rebecca Anderson and Dr Trevor Mazzucchelli. It is funded by Curtin University. There will be no costs to you and you will not be paid for participating in this project.

Why am I being asked to take part and what will I have to do?

We are looking for families with children aged 12- to 18-years who have a diagnosis of ASD, as well as symptoms including repeated, unwanted, thoughts or images, and/or compulsive behaviours such as counting, checking or cleaning, that are completed for fear of something bad happening.

Your child will be screened for ASD and OCD. Applicants with high risk of suicide or self-harm, current psychosis, or an eating disorder are currently excluded from this study, due to their need for higher levels of support.

The study involves several components: an initial telephone interview with you, the caregiver, and your child, an initial face-to-face meeting, participation in the online program, which is a weekly commitment for 8 weeks, fortnightly face-to-face sessions, and a one-month follow up appointment.

Initial Face-To-Face Meeting. At this meeting both you and your child will also be asked to complete a number of questionnaires at the Curtin Health and Wellbeing Clinic, Bentley, which include questions about your mood, level of stress, daily activities, and your child's behaviour. If you meet the study's criteria, we will send you log-in details for the online program with a timeline to complete the on-line program modules, and for face-to-face meetings.

Fortnightly Face-To-Face Meetings. At each fortnightly meeting, you and your child will meet with a provisional psychologist for 1-2 hours. We will discuss the previous fortnight's online content and prepare for the coming modules. Any questions can be addressed at these meetings. These meetings will be video recorded so the psychologist can concentrate on what you have to say and not be distracted by taking notes.

Follow up Meeting. One month after completion of the online program, you and your child will meet face-to-face with a provisional psychologist. Any final questions can be asked, and the questionnaires completed at the initial meeting will be completed, to see if there have been any changes over time.

Are there any benefits' to being in the research project?

Your child may find their symptoms change during participation in this program. As a consequence, you may find your own levels of stress and family functioning also changes.

We hope the results of this research will allow us to:

- develop education and treatment programs
- Add to the knowledge we have about co-occurring OCD and ASD, and best treatment.

Are there any risks, side-effects, discomforts or inconveniences from being in the research project?

We have been careful to make sure that the questions in the survey do not cause you any distress. But, if you feel anxious about any of the questions you do not need to answer them. If the questions cause any concerns or upset you, we can refer you to a counsellor or other suitable service for further assistance.

Apart from giving up your time, we do not expect that there will be any risks or inconveniences associated with taking part in this study.

Who will have access to my information?

The information collected in this research will be re-identifiable (coded). This means that we will remove identifying information on any data or sample and replace it with a code. Only the research team have access to the code to match your child's name if it is necessary to do so. Any information we collect will be treated as confidential and used only in this project unless otherwise specified. The following people will have access to the information we collect in this research: the research team and, in the event of an audit or investigation, staff from the Curtin University Office of Research and Development. Electronic data will be password-protected and hard copy data (including video or audio tapes) will be in locked storage.

The information we collect in this study will be kept under secure conditions at Curtin University for 7 years after the research has ended, or until your child turns 25, whichever is longest, and then it will be destroyed.

The results of this research may be presented at conferences or published in professional journals. You will not be identified in any results that are published or presented.

Will you tell me the results of the research?

We will write to you at the end of the research (in about 6 months) and let you know the results of the research. Results will not be individual but based on all the information we collect and review as part of the research.

Do I have to take part in the research project?

Taking part in a research project is voluntary. It is your choice to take part or not. You do not have to agree if you do not want to. If you decide to take part and then change your mind, that is okay, you can withdraw from the project. You do not have to give us a reason; just tell us that you want to stop. Please let us know you want to stop so we can make sure you are aware of any thing that needs to be done so you can withdraw safely. If you choose not to take part or start and then stop the study, it will not affect your relationship with the University, staff or colleagues. We will destroy any information we have collected from you

What happens next and who can I contact about the research?

If you would like to take part in this study or would like more information, please contact:
Lisa Wallace on lisa.a.wallace@postgrad.curtin.edu.au

Or The Chief investigators:

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If you decide to take part in this research we will ask you to sign the consent form. By signing it is telling us that you understand what you have read and what has been discussed. Signing the consent indicates that you agree to be in the research project and have your health information used as described. Please take your time and ask any questions you have before you decide what to do. You will be given a copy of this information and the consent form to keep.

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number 45/2013). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email hrec@curtin.edu.au.