

Professor Andrew Whitehouse
Chief Investigator
Autism Research Team, Telethon Kids Institute
100 Roberts Road, Subiaco WA 6008
Tel: +61 8 6319 1830
Email: Andrew.Whitehouse@telethonkids.org.au
www.web.uwa.edu.au/people/andrew.whitehouse

Participant Information Form

Project title: Patterns of Autistic Traits Within Families: Grandparents Survey

Name of Researchers: Autism Research Team, Telethon Kids Institute

- Prof Andrew Whitehouse (Principal Investigator)
- Dr Kiah Evans (Program Manager)
- Dr Gail Alvares (Postdoctoral Research Fellow)
- Dr Kandice Varcin (Postdoctoral Research Fellow)
- Ms Rebekka Jooste (Research Assistant)
- Ms Sarah Pillar (Research Assistant)

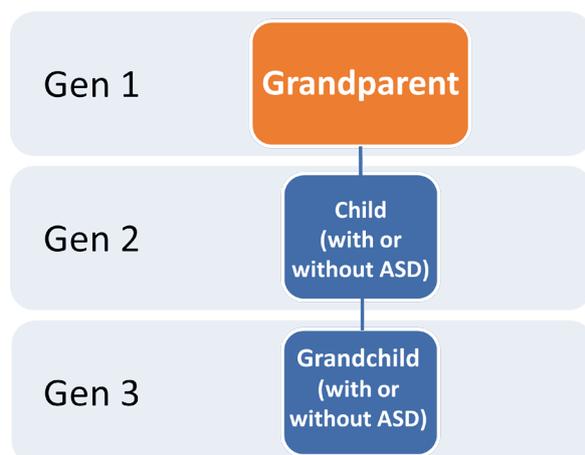
School Of Medicine, Washington University in St. Louis

- Prof John Constantino (Senior Research Leader)
- A/Prof Natasha Marrus (Principal Investigator)
- Dr Daniel Gray (Program Manager)

Invitation:

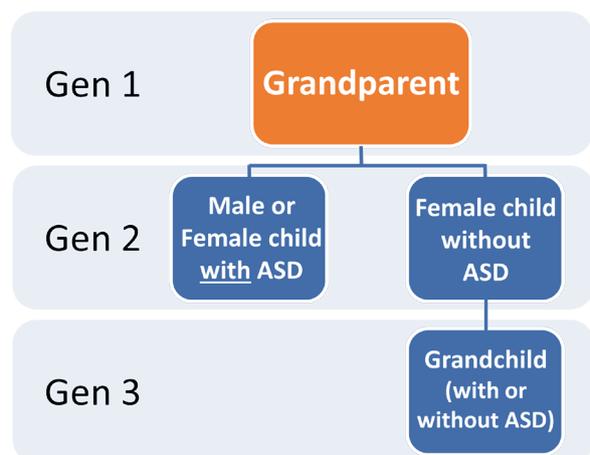
You are invited to participate in a research study being conducted by researchers from the Telethon Kids Institute in collaboration with Washington University in St. Louis (USA). You are asked to take part in this project because you are a grandparent and a biological parent and/or grandparent of an individual with autism spectrum disorder (ASD), hence you meet one of the following criteria:

Criteria A



You are a grandparent who has a biological grandchild and/ or child with autism spectrum disorder (ASD).

Criteria B



You are a grandparent who is the full biological parent of an individual with autism spectrum disorder (ASD) as well as the parent to a daughter without ASD (who also is the parent to your grandchildren).

Aim of the Study (What is the project about?)

The purpose of the study is to measure patterns of autistic traits across generations within a family. This is being studied in order to improve our standards for the timing and quality of early interventions in children with ASD and/or with social-communication differences.

What does participation involve?

If you agree to participate, we would like you to complete two surveys. You can choose to complete these surveys through a combination of online, return post or via interview (telephone, videoconferencing or in-person, depending on location), at your convenience.

The first survey should only take approximately 5 - 25 minutes. The first section of the survey will be used to discover if you meet the criteria to complete the second survey. If you do meet this criteria, you will be asked to provide family tree information via a family history and structure. This will help to make sure that the research team can include the correct questions in the second survey. If not already provided, you will also be asked to provide contact details, such as an email address, postal address or telephone number and demographic details.

The second survey involves completing some questions about your experience as a grandparent with ASD in the family. These questions take between 5-10 minutes to respond to. At this point, participants meeting Criteria A only, will have completed the study. Those that meet Criteria B, will be eligible to complete a Social Responsiveness Scales (SRS) and Social Communication Questionnaires (SCQ) about their children and/or grandchildren. The length of this second survey will vary depending on the number of children and grandchildren in your family, but we estimate this will take approximately 1 – 2 hours in total if you complete the Social Responsiveness Scales (SRS) and the Social Communication Questionnaires (SCQ).

Voluntary Participation and Withdrawal from the Study

Participation in this research is voluntary and completing the first survey is considered evidence of consent to participate in the study. You may choose not to take part at all. If you decide to participate in the study you may stop participating at any time. If you have commenced or submitted your survey, you may contact the researchers to request your information be removed from the database. You may choose to exit the survey part-way through completion and/or request to withdraw your information from the database, without reason or prejudice.

Your privacy

If you choose to participate, your participation in this study and any information you provide will be treated in a confidential manner. The full names and birthdates of you and your family members will not be requested, and you may choose to provide an alternative name (e.g. initials, nickname, or description) on the survey. We will keep the information you provide confidential by keeping all web-based information transmission encrypted on a secure website, behind two-factor authentication. All data will be managed in a de-identified format, in a password protected computer or a secure server for a minimum of seven years. Information from this project will be published but we will do so in such a way that you cannot be identified.

Possible Benefits

If you complete the SRS component of the survey will receive a small gift voucher to thank you for your participation in the research project. Other than this, you will not benefit personally from participation in this study, but you will be a part of advancing our knowledge about how ASD may be shared between generations. We hope that others may benefit in the future from what we learn as a result of this study. The study will collect data that will inform our understanding of transmission of

ASD traits within families and the emergence of ASD traits early in development. This information will help improve standards for the timing and quality of early interventions in children with ASD and/or at risk of ASD.

Possible Risks and Risk Management Plan

There are no foreseeable risks from being a part of this research, other than minor inconvenience resulting from the time taken to complete the study. You will not incur any costs for being in this research study.

Contacts

If you would like to participate or discuss any aspect of this study please feel free to contact the Research Assistants via rebekka.jooste@telethonkids.org.au or sarah.pillar@telethonkids.org.au, otherwise they can be reached on (08) 6319 1833.

Sincerely,

Chief Investigator
Professor Andrew Whitehouse

Approval to conduct this research has been provided by the University of Western Australia, in accordance with its ethics review and approval procedures (reference number RA/4/1/4120). Any person considering participation in this research project, or agreeing to participate, may raise any questions or issues with the researchers at any time. In addition, any person not satisfied with the response of researchers may raise ethics issues or concerns, and may make any complaints about this research project by contacting the Human Ethics office at UWA on (08) 6488 4703 or by emailing to humanethics@uwa.edu.au. All research participants are entitled to retain a copy of any Participant Information Form and/or Participant Consent Form relating to this research project.