

**THE
ORIGINS
PROJECT**



**TELETHON
KIDS
INSTITUTE**
Discover. Prevent. Cure.

 **Joondalup
Health Campus**
Part of Ramsay Health Care



KINDY READINESS PROJECT

IS YOUR ORIGINS CHILD TURNING THREE-YEARS-OLD?





What is the aim of this study?

The aim of the Kindy Readiness Project, an ORIGINS sub-project, is to provide an opportunity to review the development and wellbeing of your child, prior to them commencing preschool, kindergarten and/or an early learning environment.

Who is it for?

You have been invited to participate in the Kindy Readiness Project because you have a child who is close to turning three years of age and you have provided consent to be contacted regarding future studies within The ORIGINS Project.

What is required?

You will be asked to complete online questionnaires at, or around the time, your child turns three years of age. The questionnaires, which should take no more than 45 minutes to complete, will consist of:

- ▶ an internationally recognised assessment of child development (Ages & Stages Questionnaire);
- ▶ an assessment of child behaviour (Conners Early Childhood); and
- ▶ further questions about you, your child and partner's current health and medical history.

Will there be a cost to me?

You will not incur any costs through your involvement with this study. The online questionnaires and subsequent feedback are provided at no cost to you.

What are the benefits and risks of taking part?

Through completion of the online questionnaires you will have the opportunity to raise any concerns regarding your child's development, behaviour and/or wellbeing. You will be provided with a letter outlining the results. If concerns are identified, you will receive feedback and suggestions on referrals to public clinics or private allied and/or specialists via your GP.

We do not predict any risks of taking part in this study.

What will happen to the information I provide?

By signing the consent form and completing the online questions, you agree to this information (data) being stored in the ORIGINS databank for future use by researchers provided as de-identified information.

Where will the data be stored?

All online data collected will be stored within The ORIGINS Project databank on secure servers at the Telethon Kids Institute. The servers are in a secure location and access is restricted to a few individuals. Access to all areas of TKI is via secure electronic tag.

Using unique IDs your data, and that of your child, will be de-identified and stored separately from your identifiable data (i.e. your contact details). Your identifiable data are accessible only to specified members of the data management team.



Confidentiality

We are committed to protecting the confidentiality and privacy of your data. All members of the research team are required to sign confidentiality agreements. Other researchers will need to apply for approval from the Ramsay Health Care WA | SA Human Research Ethics Committee, in order to access the data. Your data will not be sold; however, researchers may be charged a fee to recover some of the costs of collecting the information stored in the ORIGINS databank. When data is released to researchers, no identifying information will be provided.

The results from research based upon the data may eventually be published in medical journals or at professional meetings, but you and your child will not be identified in any way.

In very rare circumstances, disclosure of your health information will be required by law, for example, as a result of a court order.

Participation is voluntary

Participation in the Kindy Readiness Project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine treatment, your relationship with those treating you or your relationship with the Joondalup Health Campus. It will also not affect your current involvement and consent in The ORIGINS Project.

Withdrawal

Should you choose to withdraw, the information that you have already provided will continue to be kept securely and may be used for related research unless you request the data be destroyed.

You will be provided with a withdrawal form to complete. Your signed consent and withdrawal forms will be kept as a record of your wishes. Such a withdrawal would prevent information about you from contributing to further analyses, but it would not be possible to remove your data from analyses that have already been done.

Who are the researchers leading the study?

➤ **Professor Susan Prescott**
Paediatrician and Allergy Specialist
Perth Children's Hospital
Telethon Kids Institute
University of Western Australia

➤ **Professor Desiree Silva**
Paediatrician
Joondalup Health Campus
Telethon Kids Institute
University of Western Australia

Further Information

If at any time you have any questions:

08 9408 3118

ORIGINSproject@telethonkids.org.au

Concerns?

The ethical aspects of this study have been approved by the Ramsay Health Care WA | SA Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in a research project, please contact the JHC Executive Office on **(08) 9400 9404**. Any complaint you make will be investigated by an independent party, treated in confidence, and you will be informed of the outcome.

This study is a sub-project of The ORIGINS Project. The ORIGINS Project is a collaboration between Joondalup Health Campus and Telethon Kids Institute and is funded by the Paul Ramsay Foundation and the Commonwealth Government of Australia through Channel 7 Telethon Trust.

