

**THE  
ORIGINS  
PROJECT**



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

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

# THE ORIGINS PROJECT ROUTINE DATA COLLECTION

## WHAT IS THE AIM OF ORIGINS?

Chronic conditions like diabetes, allergies, eczema, heart disease, obesity and poor mental health are affecting more of our children than ever before. There is strong evidence that the risk of developing many of these conditions may be affected by a mother's health during pregnancy and a baby's time in the womb.

The aim of ORIGINS is to find out how we can overcome these modern health conditions and shape a healthy life for kids. With your participation, ORIGINS will create a databank that can support a diverse range of research intended to examine how early life factors (the environment, genetics and parental health), can influence the health and development of the next generation of children from the first moments of life.

We are inviting all pregnant women and their families to participate in this ground-breaking research. We aim to follow the progress of this new generation of children over the course of childhood.





## PARTICIPATION IS VOLUNTARY

Participation in ORIGINS 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.

If you decide you want to take part in ORIGINS, you will be asked to sign a consent form. By signing it you are telling us that you:

- understand what you have read
- consent to take part in ORIGINS
- consent for the use of your personal and health information as described.

## WHO IS ORIGINS FOR?

Any family planning to deliver their baby at Joondalup Health Campus.

## WHERE WILL MY DIGITAL DATA BE STORED?

Data will be stored on secure servers at the Telethon Kids Institute. The servers are in a secure building and access is restricted to a few named individuals. To enable data linkage with your records held by the Australian Government, such as the Child and Adolescent Health Services, we will share demographic information (e.g. name, date of birth). Your identifiable data are accessible only to specified members of the data management team.

## COLLECTION OF YOUR ROUTINE DATA

If you would like to participate in ORIGINS by contributing information routinely collected, we invite you to allow us to collect data about you and your child from:

- (i) your records held at the Joondalup Health Campus. This includes your weight, height, blood pressure measurements, allergies, medications prescribed, glucose tolerance test result;
- (ii) routinely collected biological samples (such as blood, urine);
- (i) Your records held at other health and allied services e.g. immunisation records, GP records, hospital admissions in WA; and,
- (ii) data linkage to collections held by the Australian Government, such as prescription medicines dispensed by pharmacies and childhood immunisation records; and
- (v) your records held at private and government health services e.g. the Government of Western Australia Child and Adolescent Health Service.





## WHERE WILL MY ROUTINE SAMPLES BE STORED?

The ORIGINS Biobank sponsor is Western Diagnostic Pathology (WDP). WDP staff process the majority of the ORIGINS biological samples at the WDP state laboratory. The remainder of the biological samples are processed at the Telethon Kids Institute within the Perth Children's Hospital. The ORIGINS Biobank will be stored long-term at this site, as well as on the premises of a Telethon Kids Institute subsite in Subiaco.

## CONFIDENTIALITY

The ORIGINS team are committed to protecting the confidentiality and privacy of the data. All members of the ORIGINS team are required to sign confidentiality agreements. Researchers will need to apply for approval from the Ramsay Health Care WA / SA Human Research Ethics Committee in order to access the ORIGINS databank. 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 ORIGINS databank 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.

## WITHDRAWAL


Should you choose to withdraw, the information that you have provided will continue to be kept securely and used for ORIGINS related research projects unless you request for them to be destroyed. 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 had already been done.

## KEEPING IN TOUCH

The ORIGINS website is a great way to keep up to date with the latest ORIGINS news.

If at any time you have any questions:

 08 6375 6300

 [ORIGINSproject@telethonkids.org.au](mailto:ORIGINSproject@telethonkids.org.au)

 [ORIGINSproject.telethonkids.org.au](http://ORIGINSproject.telethonkids.org.au)

## ANY CONCERNS?

The ethical aspects of this study have been approved by the Ramsay Health Care WA | SA Human Research Ethics Committee (RHC WA | SA HREC). If you have any complaints or reservations about any ethical aspect of your participation in a research project, please contact the Consumer Liaison Office at Joondalup Health Campus on (08) 9400-9404 who will direct your complaint to the most appropriate person. Any complaint you make will be investigated by an independent party, treated in confidence, and you will be informed of the outcome.

## WHO ARE THE RESEARCHERS LEADING ORIGINS?

### CO-DIRECTORS

#### **Prof Desiree Silva**

**Paediatrician & Director of Research**

Joondalup Health Campus

Telethon Kids Institute

The University of Western Australia

#### **Prof Susan Prescott**

**Paediatrician & Allergy Specialist**

Perth Children's Hospital

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