

WHO IS CARRYING OUT THE STUDY?

The *Early Moves* study is being led by Dr Jane Valentine and Prof Catherine Elliott from the Kids Rehabilitation Department at Perth Children's Hospital. The study also involves ORIGINS Project investigators Prof Susan Prescott and Prof Desiree Silva from the Telethon Kids Institute, Joondalup Health Campus, Curtin University, Deakin University, the University of Western Australia and the Australasian Cerebral Palsy Clinical Trials Network Centre for Research Excellence.

ETHICAL INFORMATION

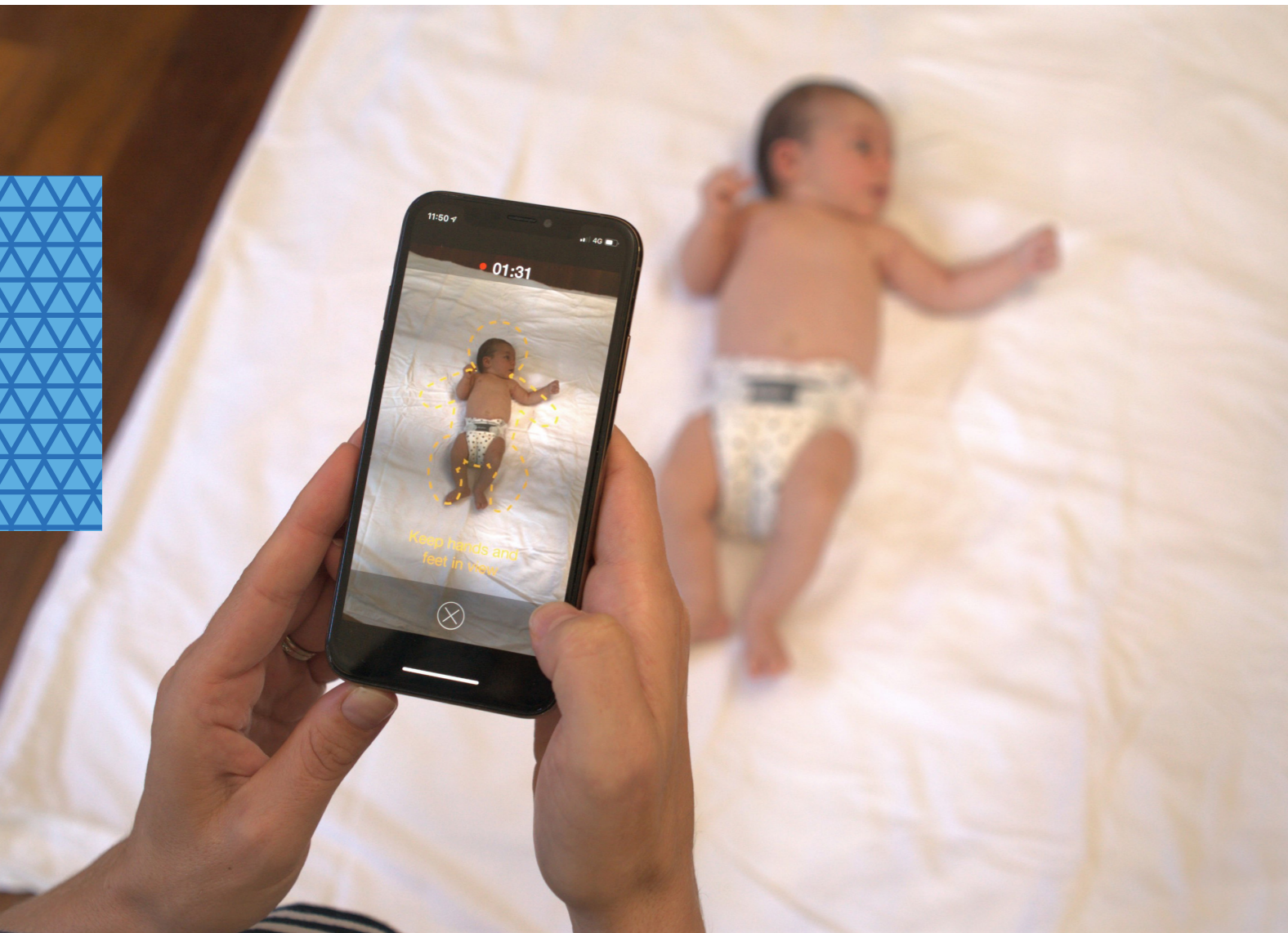
The ethical aspects of this study have been approved by the Ramsay Health Care WA | SA Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in a research project, please contact Joondalup Health Campus Executive Office on (08) 9400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

THE
ORIGINS
PROJECT



TELETHON
KIDS
INSTITUTE
Discover. Prevent. Cure.

Joondalup
Health Campus
Part of Ramsay Health Care



THE EARLY MOVES STUDY



ANY QUESTIONS?

If you would like further information about this study, please do not hesitate to contact

Dr Caroline Alexander on 0434 938 571 or email earlymoves@health.wa.gov.au.

Information can also be found on our website: originsproject.telethonkids.org.au/sub-projects.



HOME VIDEOS ARE BEING USED TO DETECT IF
A CHILD HAS DEVELOPMENTAL DIFFICULTIES IN
THIS WORLD-FIRST RESEARCH PROJECT.



WHAT IS EARLY MOVES?

The *Early Moves* study, a sub-project of [The ORIGINS Project](#), is investigating whether a baby's early movements can predict learning difficulties later in childhood.

WHY ARE WE DOING THIS STUDY?

This study will help us to better understand how to recognise developmental difficulties early enough to provide support and intervention when babies' brains are most able to benefit in the first year of life, a critical period of brain development.

We think that the movement pattern in very young babies may help us predict learning difficulties. Babies' early movements develop in a very particular way, and this changing pattern of movements shows that the brain and nervous system are developing well. Sometimes, however, the brain and nervous system don't develop normally, and this can indicate they baby may be at risk of developmental disorders.

We are currently unable to reliably identify difficulties at such a young age. Predicting learning difficulties early means we can give the babies the best possible start to life by offering early intervention and support when their brain is developing rapidly.

WE INVITE YOU TO TAKE PART

We are inviting you to consider taking part in this research study because you have agreed to be part of The ORIGINS Project. We are aiming to involve 3000 ORIGINS babies in this study.

- ▶ Before you decide whether to take part, it is important for you to understand why the research is being undertaken and what is involved for participants in the Early Moves Study.
- ▶ Please read this information carefully. Talk with your friends and relatives if you wish.
- ▶ Ask questions about anything that you don't understand or want to know more about.
- ▶ You are free to decide whether or not to take part in this study. Regardless of your decision, your family's health care will not be affected in any way.

WHAT DOES MY PARTICIPATION INVOLVE?

If you choose to take part in this study, we will follow your baby's development until they turn two years old. We know that life can be busy when you have young children, and life with a newborn is a very unique and special time, so we have tried to make participating in this research simple and easy for you. A lot of it you can do from home, in your own time.

▶ Installation of a smartphone app on your mobile device

Before you leave the hospital after having your baby, a researcher will pay you a quick visit to help you install our specialised smartphone app, Baby Moves. This app was developed to allow you to collect videos of your baby at home, and send them to us for assessment.

▶ Recording your baby

So we can assess your baby's movements, you will be asked to take short, three-minute videos of your baby using the Baby Moves app and upload them directly to our secure database. You will be asked to take these videos at 1, 3, 12 and 14 weeks post-term age (baby's age calculated based on their due date, not birth date). The app will send you notifications to remind you it is time to take the video.

▶ Remote assessment of your baby's movements

We will conduct a specialist assessment of your baby's movements using the videos you upload to the secure database, so there is nothing further for you to do. Our assessors are highly trained and experienced in these assessments, but even then it takes some time to complete. To reduce the time and costs of the assessment, in the hope it will one day be available to every child in Australia, we will be developing an automated scoring system using machine learning and advanced image recognition techniques.

▶ Developmental assessment

The developmental assessment is the final activity for this research project and takes place when your child turns two years old. This standardised play-based assessment measures your baby's language and cognitive development, among other things. It normally takes no more than one hour, and often less, and an appointment at JHC will be arranged to conduct the assessment.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

Participants will receive an early screening for risk of cerebral palsy through the 12 -14 week video assessment, and a full developmental assessment of your baby when he/she is two years old. Should any concerns be identified at either assessment, you will receive the best care and support to address these concerns. By being part of this study, you and your child could also be involved in an important scientific advance.

WHAT ABOUT PRIVACY?

The videos you record through the app are uploaded directly to the research centre by you. This is a secure process, and the videos can only be accessed by authorised researchers on the *Early Moves* team. The information we collect from the videos, questionnaires and assessments is kept strictly confidential. As soon as you join the study, you and your child will be allocated a code number, so no identifying details will be stored with your study information. We will never publish your images or identifying information.

WHAT IF I CHANGE MY MIND?

Even if you consent to take part, and change your mind later, that is OK. You can withdraw from the *Early Moves* study at any time, and you don't have to explain why. Withdrawal will not affect your involvement in ORIGINS, or the care you receive. If you withdraw, the information we collected may still be used.

WHAT HAPPENS TO THE RESULTS OF THE STUDY?

At the end of the study we will send you a project summary booklet that gives results of our research. We also plan to publish our findings in scientific journals, and the results may appear in the media. Under no circumstances will you be identified in any publications.

