



# THE EARLY MOVES STUDY

INVESTIGATING WHETHER A BABY'S EARLY MOVEMENTS CAN  
PREDICT LEARNING DIFFICULTIES LATER IN CHILDHOOD

IMPLEMENTING  
PARTNERS:



**Curtin University**



## 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 developmental disorders. 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 the baby may be at risk of developmental disorders, including learning difficulties and autism spectrum disorder.

We currently are unable to reliably identify difficulties at such a young age. Predicting 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. We are aiming to involve 3000 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. Participation in the study includes:



### Installation of a smartphone app on your mobile device

A researcher will 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 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. Videos will be assessed by an experienced trained clinician. Automated scoring using advanced machine learning techniques will also be developed as part of the project, making assessments quicker, cheaper and more accessible.



## Two year old assessment

- The **developmental assessment** is a standardised play-based assessment that measures your baby's language and cognitive development, among other things at age 2. It normally takes no more than one hour, and often less. An appointment at St John of God Midland, or a nearby health service, will be arranged to conduct the assessment. At the time of this assessment, you will also be asked to complete the following questionnaires.
- **Screening for early signs of Autism Spectrum Disorder (ASD):** You will be asked to complete a short questionnaire about your child's usual behaviours. If your response indicates a higher risk of Autism Spectrum Disorder, we will offer further assessments and referrals as needed to ensure you and your child get the best support.
- **A questionnaire on Carer Quality of Life:** This asks about your experience caring for your child and the impact on your quality of life, helping us understand the personal impact of raising a child with and without developmental disorders.
- **A questionnaire about Health Resource Use:** This asks for information about your use of private health services and external care for your child, helping us understand the financial impact of raising a child with and without developmental disorders.



## Allowing us to access your baby's medical information

The researchers will link the research data to routinely collected health and medical data relating to your pregnancy and birth and your child's use of health services. This data will be used to identify if there are any other risk factors for developmental difficulties.



## What additional information about my child will be accessed?

The Department of Health collects important health and medical information about the patients accessing services and the care provided to them. So we can understand more about your child's health and development in the first 6 years of their life, and the financial impact of this, we require data from these databases:

- Medicare and Pharmaceutical Benefits Scheme claims (information on your child's doctor visits and the associated costs [Medicare] and prescription medications you have filled for your child [Pharmaceutical Benefits Scheme])
- Midwives Notification System (health and medical information about the pregnancy, labour and birth of your child)
- WA Register of Developmental Abnormalities (if applicable, any diagnosis of a developmental anomaly your child has received)
- Emergency Department (ED) Data System (when and why your child visited the ED and the care they were provided)
- Hospital Morbidity Data System (when and why your child was admitted to hospital, and the care provided to your child)
- Child Development Services (CDS) Database (if applicable, any referrals your child has had to child development services, as well as clinical contacts including assessments and treatments)

## 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.

## When will I hear about the outcomes of the assessments?

Our researchers may contact you for a number of reasons after each video or assessment, including if the video quality has made it difficult to assess and we need you to take another video. We will also contact you if the assessments identify differences in your baby's movements at 12 or 14 weeks. Differences in the videos at these time points can indicate risk of neurodevelopmental disorders so our team will discuss this with you and will arrange for you and your baby to visit the Early Intervention Clinic at Perth Children's Hospital for a comprehensive review. If there are any concerns identified from the developmental assessment when your baby is two, we will also discuss this with you and refer you to the appropriate services.

## What are the possible benefits of taking part?

Participants will receive an early screening for risk of cerebral palsy through the 12 to 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 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 the care you receive. If you withdraw, you will not be followed up and the information we have already collected will 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.

## Who is carrying out the study?

Early Moves is led by Professor Jane Valentine at Perth Children's Hospital and Professor Catherine Elliott at Curtin University, in partnership with the ORIGINS Project (a collaboration between Joondalup Health Campus and Telethon Kids Institute) and St John of God Midland Public and Private Hospitals.

## Ethical information

The St John of God Health Care Human Research Ethics Committee has given ethical approval for the conduct of this study. If you have any concerns or complaints regarding this study, you can contact the Executive Officer of the Committee (telephone number (08) 9382 6940) on a confidential basis. Your concerns will be drawn to the attention of the Committee that is monitoring the study.

## Questions?

If you would like further information about this study, please do not hesitate to contact Sarah Hall by phone or email:

**0479 186 027 | [earlymoves@curtin.edu.au](mailto:earlymoves@curtin.edu.au)**



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Department of Health



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