

# GETTING A HEAD START ON HEALTH ISSUES

The ORIGINS Project, a collaboration between Telethon Kids and Joondalup Health Campus, is collecting data and biological samples from 10,000 families over 10 years to create one of the largest data and biobanks in Australia. Its work is also giving participating families a valuable heads up on health issues, including severe allergies, delayed speech and physical development, and anxiety and depression in mums.



Dr Jamie Tan with ORIGINS Participant



A decision to include a critical element in the ground-breaking [ORIGINS Project](#) is helping to identify health issues among participating babies, toddlers and parents – leading to specialist referrals and enabling early intervention.

Although ORIGINS is not an intervention study, Co-Directors Professor Desiree Silva and Professor Susan Prescott decided to incorporate 'real-time feedback' into the protocol – essentially allowing researchers to let participants know as soon as a health issue is identified.

"As well as enabling strategic long-term research capacity, ORIGINS is a responsive system for parents and their children, with translation to

clinical and diagnostic services," paediatrician Professor Silva said.

"We felt it was essential that our participant families were privy to any results that we learned through our assessments, so they could then be addressed as soon as possible."

ORIGINS participants complete online questionnaires, Ages and Stages questionnaires and send in urine, stool, cheek swab and saliva samples at regular intervals throughout their child's first year, with the material periodically reviewed by a consultant paediatrician. The questionnaires and sample drop-offs then continue every 6–12 months until the child is five years old. Face-to-face assessments are also conducted as part of the project, at one, three and five years of age.

The online questionnaires include questions about the child's diet, health, environment and developmental milestones, as well as information about the parents' lifestyle, environment and health.

Consultant paediatrician Dr Jamie Tan has been part of The ORIGINS Project since its inception in 2017.

"If the baby or child is below the screening cut-off for their developmental assessment, we will contact the family and recommend they come in and see me or their own paediatrician," Dr Tan said. "If it's only a mild concern, we'll still let them know to get it checked out by their GP or child health nurse.

"We've identified many issues over the three years the study has been running. A common one is iron deficiency – you'd be surprised how many kids are low in iron. In fact, at the three-year appointment conducted as part of The ORIGINS Project, iron studies are now routinely sent off to enable some real-time feedback."

The team has also identified severe allergies, eczema, undiagnosed hip dysplasia, and psychosocial and developmental delays in ORIGINS kids, referring them to appropriate services including GPs, specialists and allied health r community support services.

"Sometimes parents will actually contact ORIGINS about concerns they have about their child," Dr Tan said.

"Subsequently the ORIGINS staff member will contact me or one of the other consultant paediatricians for follow up with the family." Professor Silva said every child within the ORIGINS Project received real-time feedback.

"To date, 48 per cent of babies at their one-year check have had an issue identified and a management plan provided," she said. "The children definitely benefit from the early intervention, as so many issues can be addressed if a medical team gets onto them quickly."



## What's next?

- ORIGINS will look to increase the diversity of study participants by targeting disadvantaged and vulnerable groups in regions of Perth with high need.

*The ORIGINS Project is a collaboration between the Telethon Kids Institute and Joondalup Health Campus, which is part of Ramsay Health Care. The project is funded by the Paul Ramsay Foundation and the Commonwealth Government through Telethon.*

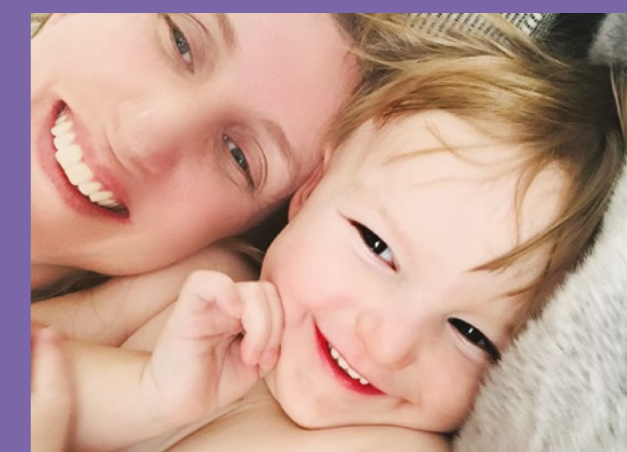
## REAL-TIME FEEDBACK PICKS UP DELAY

ORIGINS participant Nina Dorieux knows the benefits of real-time feedback. When son Noah, who was 7 months old at the time, was identified with speech and developmental delays through his ORIGINS assessments, Dr Tan quickly responded and let her know a follow-up was needed.

"There were some things that we had noticed with Noah's development, but sometimes as a mum, you don't want to appear paranoid, so you let them go," Nina said. "When the ORIGINS Team got in touch to let me know that it would be a good idea to see a physio, I was grateful that my concerns were validated."

Noah is now two years old and has been seeing a physio and getting help with his speech and hearing.

"I definitely don't think we would have had the same access to specialists and resources to support us with Noah if we weren't part of the ORIGINS cohort," Nina said.



Nina Dorieux with son Noah

"His delays were identified earlier than they would have been otherwise, say at the standard one-year paediatric check-up, and I have no doubt he is developing better because of that earlier intervention."