

FirstWord

LOOKING
at Language

March 2010

Newsletter of the LOOKING at Language Study

1000 WA twins help language research

Perth researchers are using the DNA of twins and their families to help investigate how many genes may contribute to language, speech and reading problems in young children.

The study of language and literacy development which tracks children from the age of two to nine is believed to be the first of its kind in the world and is helping establish the extent to which developmental delays are due to children's genetic make-up rather than their environment.

It is known as the Looking at Language study and researchers from the US, Perth's Telethon Institute for Child Health Research and Curtin University are tracking 1000 WA twins and their families over 10 years.

While most of the children, including eight-year-old identical twins Zoe and Tara Dixon of Karrinyup, will go on to have normal language development, those who struggle to talk or read could give valuable clues to researchers.

Principal investigator Professor Mabel Rice, from the University of Kansas, said the research had been boosted by the discovery of a gene known as KIAA0319 that appeared to have a double effect in children's development, contributing to language problems and the reading disorder dyslexia.

This could help explain why many children who had language difficulties went on to become struggling readers.

"The exciting thing about this is that this is a gene which has not previously been found to affect language and so this is adding a new track to the study of twins because we know now that is one of the first things we would be looking for in their



DNA," she said.

"This study in Perth is a rare opportunity in the scientific world to apply this finding and look for other genes and see how children develop over time."

It could explain to parents and teachers why some children tried hard to learn but still struggled. She said it was like expecting short children to work harder at becoming tall.

Article by Cathy O'Leary, Medical Editor, 21 October 2009. Copyright The West Australian Newspaper. Used with permission.

Slowly but surely, the jigsaw takes shape...

The Australian Twin Registry (ATR) published the following article in their 2008 newsletter and we wanted to share it with LaL families.

The ATR receives many calls from twins and their families who are naturally curious about the results of the research they have participated in. It is very reassuring for them to hear that their involvement has had some sort of tangible benefit.

Research can be a painstakingly slow process. Each study is like a single piece of a large jigsaw puzzle – the results from each study often adds only a small part to the overall picture. It can take years of work to find answers to the questions that researchers are asking about specific diseases and traits in the population.

So why does it take so long for us to see the full picture? Let's consider the life cycle of a typical research study.

The initial stage of a twin research project run in conjunction with the ATR begins with an Expression of Interest – this is where researchers have an idea for a scientific question, and start working out ways to get an answer. These scientific questions need to be very precise and defined so that the researchers know exactly what they are looking for.

The ATR works closely with researchers during this phase; sharing examples of other studies conducted in the same area, brainstorming options for recruitment and selection of twins and writing detailed research plans to make sure everyone's thinking on the same level. We also put researchers in touch with others in the field who work on similar issues. The ATR reviews the final plan using independent experts in the area to make sure the research will be of benefit to the scientific community.

Once the research plan is formulated, the ATR and researchers develop a letter inviting twins to participate. This is an important step, as we need to make sure that our members fully understand what is being asked of them – we may only have one chance to introduce a new study to the twins and if they are confused by our letter, or the study seems too much trouble, they may choose not to participate.

The research documents and plans are then

assessed by a Human Research Ethics Committee. These committees are set up in each hospital and university, and give the final and essential approval for studies to start. Often the Ethics Committee will require changes to the plans or documents. (It is the Committees' role to act on behalf of research participants to ensure that all studies are ethically sound and safe, and will not adversely affect the participant, and if this means that the research is delayed then so be it!) Research involving people cannot under any circumstances proceed until the relevant Ethics Committee has approved the study.

The next stage is when twins themselves get involved! The ATR sends out letters describing the new study and twins decide if they want to be involved or not and send back a response form indicating their choice. Responses are received by the ATR and we record whether or not the twin/s (or the parents for studies where the twins are under 18) want to be involved. If both twins are interested in being involved in the study, we then send a copy of the response forms to the researchers. The researchers then organise interviews and/or appointments with the participants so that data collection can begin.

And you thought that was a lengthy process? Now comes the time consuming bit – data collection. Naturally the time it takes to complete data collection depends enormously on the number of participants involved and the type and amount of information to be collected. For example, some of our researchers want to talk with only a handful of twin pairs (maybe a few hundred or so) but others want to involve thousands of pairs – this is often because the question that the researchers are trying to answer is difficult and requires the input of many participants in order to get a clear picture of the answer.

The type of information collected also varies – some studies simply involve a single questionnaire, for example, the recent study we ran on *Folate During Twin Pregnancies* asked a set of questions over the phone. Other studies are much more detailed, for example the *Tooth Emergence Study*, which involves data collection over a number of months while the twins' teeth are coming through. *The Transition to School Study* asked a set of questions before the twins started school, some questions after they started school, and a few more questions a year later. The twins' teachers were also involved, and the twins themselves did sticker activity sheets, with

some twins also taking part in a videotaped session while playing with their friends.

Other studies (usually involving adults) ask for blood tests or scans and measurements. Overall this data collection period can span months or even years.

After the data collection is completed, statisticians are brought in to check the data, analyse patterns and work out ways to interpret the huge amount of evidence collected. The researchers then collaborate with each other and with other scientists internationally to determine what story the information is telling them. This can confirm what the researchers were expecting the data to show, or present a totally different outcome to what they were expecting.

Once the data is understood, researchers write scientific articles explaining the data which are published in scientific journals – these journal publications are collections of articles in one particular field of work, such as cancer research, or diabetes. This is a vital part of the scientific process as it allows other researchers with expertise in that area to scrutinise and challenge the data and results.

Often different groups of researchers work on similar projects and each different project can yield alternative ideas regarding the answer to the scientific questions posed. This process can sometimes seem repetitive, but it is the fundamental basis of the development of the theory of science – that studies and results are repeatable and can be verified by other groups.

Journals also provide the ability for researchers to collate all the information on a particular area, to determine where the gaps in understanding are, and therefore determine the next research questions that need to be asked. And because each new result often adds only a small piece to the overall “jigsaw puzzle” of a disease, the research questions often build on each other to eventually form the big picture.

As you can see, in research at least – all good things take time!

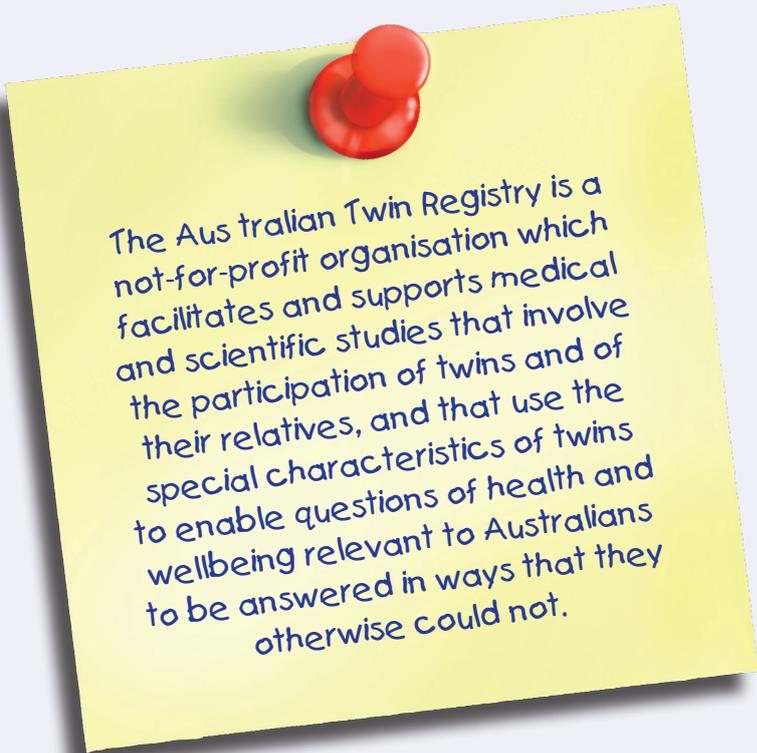
Take, for example, one of our current projects: the *Genetics of Cannabis Use and Mental Health in Australia Study*. It is a telephone interview-based study conducted by the Queensland Institute for Medical Research in conjunction with Washington University and targets twins born between 1972

and 1979. Initial work with the ATR on developing this study began in early 2005 and letters inviting the first set of participants started being delivered in October 2006. The study is looking for over 8,000 participants, and recruitment will be ongoing until they reach this target – on current projections this will be sometime in 2009.

Understandably it will be years before the collection of data for this study is completed and results start to be interpreted and written up. Research into cannabis use is not new; recently results were posted from a similar study in the UK, emphasising the necessity of being able to reproduce studies to confirm results.

Scientific research is far from a straight-forward process. It involves many twists and turns before it reaches conclusions that, hopefully, will have far reaching implications. By participating in this research, our members play an integral part in the development of many ground-breaking studies which contribute to the health and wellbeing of the whole population. Rest assured that one day the results of your contribution will be analysed, reported and maybe even save lives – it just might take a little longer than you expected!

*Reproduced with the kind permission of the Australian Twin Registry from the 2008 TWINS newsletter
www.twins.org.au 1800 037 021*



The Australian Twin Registry is a not-for-profit organisation which facilitates and supports medical and scientific studies that involve the participation of twins and of their relatives, and that use the special characteristics of twins to enable questions of health and wellbeing relevant to Australians to be answered in ways that they otherwise could not.

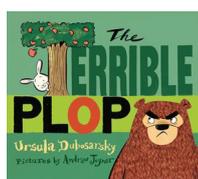
The second half of the **LOOKING at Language Study** At-a-glance

How to read this chart: Find your twin or singleton's year of birth and read down the column. The chart shows when we are likely to contact you or your family members over the next few years - what contributions you've all made!

LOOKING at Language Study Year	SINGLETONS Born 1995/1996	TWINS Born 1997/1998	TWINS Born 2000/2001	TWINS Born 2001/2002	TWINS Born 2002/2003
6 2007-2008		10 yrs MAIL CONTACT	7 yrs MAIL CONTACT	6 yrs TWIN CONTACT	5 yrs MAIL CONTACT
7 2008-2009	SINGLETON & FAMILY MEMBER CONTACT	11 yrs TWIN CONTACT	8 yrs MAIL CONTACT	7 yrs MAIL CONTACT	6 yrs TWIN CONTACT
8 2009-2010	SINGLETON & FAMILY MEMBER CONTACT	12 yrs FAMILY MEMBER CONTACT	9 yrs TWIN & FAMILY MEMBER CONTACT	8 yrs FAMILY MEMBER CONTACT	7 yrs FAMILY MEMBER CONTACT
9 2010-2011		13 yrs FAMILY MEMBER CONTACT	10 yrs FAMILY MEMBER CONTACT	9 yrs TWIN & FAMILY MEMBER CONTACT	8 yrs FAMILY MEMBER CONTACT
10 2011-2012		14 yrs FAMILY MEMBER CONTACT	11 yrs FAMILY MEMBER CONTACT	10 yrs FAMILY MEMBER CONTACT	9 yrs TWIN & FAMILY MEMBER CONTACT

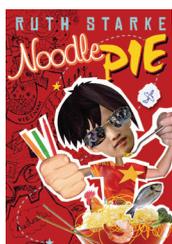
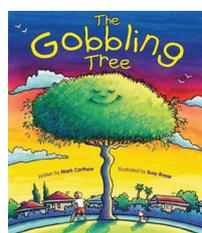
Book of the Year Award Winners Best Books for Language Development

This initiative by Speech Pathology Australia promotes quality Australia children's language and literacy, enhances people's awareness of the role speech pathologists play in literacy development and encourages a love of learning from books. The 2009 Awards recognised books in the following categories:



Young Children (2 - 5 years)
Ursula Dubosarsky for
The Terrible Plop

Lower Primary (5 - 8 years)
Mark Carthew for
The Gobbling Tree



Upper Primary (8 - 12 years)
Ruth Starke for
Noodle Pie

For more information about Speech Pathology Australia and the book awards go to: www.speechpathologyaustralia.org.au



Principal Investigator:
Mabel Rice, University of Kansas.

Co-Principal Investigators:
Associate Professor Kate Taylor and Professor Stephen Zubrick, Centre for Developmental Health, Curtin University of Technology and the Telethon Institute for Child Health Research.

This 10-year study (2002-2012) is funded by the USA National Institute of Deafness and Communication Disorders Award 2R01DC05226

LOOKING at Language is grateful for the support of the following organisations:



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